To Know or Not to Be

Vellinga, A.

2006

To Know or Not to Be

Development of an instrument to assess decision-making capacity of cognitively impaired elderly patients

The study presented in this thesis was conducted at the Institute for Research in Extramural Medicine (EMGO Institute), the department of Medical Ethics and Philosophy (VU Medical Center Amsterdam), and the department of Psychiatry (VU Medical Center Amsterdam). The EMGO Institute participates in the Netherlands School of Primary Care Research (CaRe). Which was acknowledged in1995 by the Royal Netherlands Academy of Arts and Sciences (KNAW). The study was funded by grants of the Dutch Ministry of Health, Welfare, and Sports (Ministerie van Volksgezondheid, Welzijn en Sport), the Fund Mental Health, and the BAVO foundation.

FONDS PSYCHISCHE GEZONDHEID

The printing of this thesis was financially supported by: Lundbeck and the EMGO Institute
Cover design: Rein Vellinga
Desk Top Publishing: FRANSSEN DTP
Printed by: Drukkerij Nivo, Delft

ISBN: 90-9020757-0

VRIJE UNIVERSITEIT

To Know or Not to Be

Development of an instrument to assess decision-making capacity of cognitively impaired elderly patients

ACADEMISCH PROEFSCHRIFT

ter verkrijging van de graad Doctor aan
de Vrije Universiteit Amsterdam,
op gezag van de rector magnificus
prof.dr. T. Sminia,
in het openbaar te verdedigen
ten overstaan van de promotiecommissie
van de faculteit der Geneeskunde
op vrijdag 7 juli 2006 om 15.45 uur
in de aula van de universiteit,
De Boelelaan 1105

door

Astrid Vellinga

geboren te Harlingen

promotoren:	prof.dr. C. Jonker prof.dr. E. van Leeuwen
copromotoren:	prof.dr. W. van Tilburg dr. J.H. Smit

Beoordelingscommissie: dr. R.L.P. Berghmans
prof.dr. J. Legemaate
prof.dr. M. Olde-Rikkert
dr. A.F. Tholen

CONTENTS

chapter

I

General Introduction

General introduction

Can a demented person be considered competent to make a treatment decision? Competence is a complex concept with ethical, legal, and psychological aspects. Discussions about the concept of competence can be held on different levels. In the following paragraph we will introduce briefly the ethical and legal aspects in order to explain the current position of competence in health care. In the section 'Definitions and characteristics' the normative and psychological aspects will be discussed, and we raise the question why, in some circumstances, patients with dementia are competent enough to make decisions.

Introduction

Within the context of daily medical practice, competence is usually assessed implicitly. However, in some clinical settings competency regularly becomes problematic, especially when there raises concern about the cognitive capacities of patients, and in particular those of patients with dementia. Not unexpectedly, studies have shown that persons with dementia or cognitive impairment were more likely to be incompetent or to have impaired decisional abilities than their elderly peers without these diagnoses (Kim *et al.*, 2002). In studies conducted in nursing homes high prevalences of decisional impairment were found, ranging from 44% to 69% (Royall *et al.*, 1997). Although these results may not be surprising, they nevertheless reinforce the important ethical statement that the diagnosis of dementia does not automatically imply incapacity. Studies focusing on patients in the early stages of dementia underline the great variation in the decision-making capacity of these patients. Close inspection of the results of the Marson et al. study (1995) revealed that although all the patients with mild-to-moderate Alzheimer's disease (AD) (mean MMSE 19.4) were impaired on the legal standard of 'understanding' in making decisions, 28% to 83% still had adequate decisional abilities on the other relevant legal standards of 'appreciation', 'reasoning', or 'choice'. Stanley et al. (1988) reported that the quality of the reasoning of AD patients and their comprehension of risks and benefits were similar to those of elderly control subjects. Two other studies (Bassett, 1999; Kim *et al.*, 2001) reported that the performance of 34% of the mild-to-moderate AD patients (mean MMSE 22.9) was above a validated threshold on all four standards of decision-making ability. These figures demonstrate that even if the decisional ability of 'understanding' is impaired, at the same time there can still be unimpaired abilities of 'appreciation', and 'reasoning'. These findings give rise to the question of how can we explain that in patients with dementia a more complex decisional ability of 'appreciation' is less impaired than the basic decisional ability of 'understanding'? Before generating research questions to obtain more insight into this issue, the concept of competence will be briefly introduced.

Ethical background

Since the nineteen seventies biomedical ethics has been profoundly influenced by four principles: the principle of respect for autonomy, the principle of non-maleficence, the principle of beneficence, and the principle of justice (Beauchamp & Childress, 1994). Respect for autonomy refers to recognizing the other person's capacities and perspective and treating the other in such a way as to allow or enable him or her to act according to his or her perspective (Beauchamp & Childress, 1994). Beneficence refers to prevent and remove evil or harm, and to promote or do good (Beauchamp & Childress, 1994). In present day health care respect for autonomy means that patients are allowed to make their own decisions, free from the influence of others, as long as they promote their own well-being. When patients are inclined to make decisions which may harm their own well-being (according to health care standards or their family), a discussion may arise to determine the degree to which the patient is competent to make those decisions. Therefore, competence has been described as a hinge between the values of autonomy and beneficence.

Attention has to be given to the issue of competence as a condition in the procedure of informed consent. Informed consent arose as a concept within the context of human experimentation after the Nuremberg trials (Appelbaum & Roth, 1982), although it had already been introduced in Germany in 1900 (Vollmann & Winau, 1996). It has become influential in health care research since the nineteen seventies and implies that physicians

are obliged to disclose certain information to enable the patient to decide whether to consent or to refuse participation in research. It is important that the patient can understand the information, is allowed to make the decision voluntarily, and is able to withdraw from the experiment whenever he/she wishes. The presumption is that patients are just as competent to consent to participate in research as they are to make treatment decisions. Although informed consent in research can be seen as a construct to protect people, it has now become a cornerstone concept in health care, expressing respect for the patient's autonomy.

Legal background in the Netherlands

In the Netherlands several laws protect patient rights: the Special Admissions to Psychiatric Hospitals Act (1992)[1], the Contract of Medical Treatment Act (1994)[2], the Organ Donation Act (1996)[3], the Medical-Scientific Research on Human Subjects Act (1998)[4], and the Euthanasia Act (2001)[5] (Welie *et al.*, 2005). The Contract of Medical Treatment Act (WGBO) and the Special Admissions to Psychiatric Hospitals Act (BOPZ) are the guiding principles in mental and psycho-geriatric health care.

The Contract of Medical Treatment Act (WGBO) provides a legal basis for the (voluntary) care of somatic patients, for the care of psychiatric patients, and also for the somatic care of involuntarily committed patients. The Act conceptualizes the relationship between the patient and the health care professional as a contract. It explicates the rights and duties connected with the informed consent doctrine. It states that 1) the health care professional is obliged to provide the necessary information to the patient, in order to guarantee that the patient has a choice, 2) the patient must make this choice voluntarily, free from any third party interest, and 3) the patient is assumed to be competent. The health care professional assesses whether or not the patient is competent and is responsible for the possible outcome. In some rare cases however, the competence is assessed in a legal procedure, in which all persons are assumed to be competent until evidence of the opposite is given and accepted in court.

The Special Admissions to Psychiatric Hospitals Act (BOPZ) deals with the criterion of danger, and not competence. If the patient is deemed to be dangerous as a result of a psychiatric disease, the psychiatrist must obtain permission from a civil authority, such as a mayor, in order to detain the patient against his/her will. Treatment is justified if a competent patient consents, or in case of incompetent patients, if a representative consents. In case of resistance to treatment by the patient or representative, forced treatment is possible if the patient is considered to be dangerous or harmful to himself or to others, regardless of the patient's competence or incompetence.

There are no clear criteria for competence in the Dutch law. Competence in the WGBO is defined as follows: a person is competent if he/she is considered to be able to make a reasonable judgement in the light of his/her own interests at hand. In 1994 a governmental committee, established by the Minister of Justice and the Secretary for Public Health, stated in guidelines for the assessment of competence that a person can be considered competent "if he/she shows understanding of the information which is attuned to his/her comprehension, to such an extent as is necessary in view of the nature and scope of the decision at hand" (Ministerie van Justitie, 1994).

[1] Wet Bijzonder Opnemingen in Psychiatrische Ziekenhuizen (BOPZ); Wet van 29 oktober 1992, Stb. 1992, 669.

[2] Wet op de Geneeskundige Behandelings Overeenkomst (WGBO); Wet van 17 november 1994, Stb. 1994, 837 j° 838. It takes up the articles 446-468 of book 7BW.

[3] Wet op Orgaandonatie; Wet van 24 mei 1996, Stb. 1996, 370.

[4] Wet Medisch-wetenschappelijk Onderzoek met mensen (WMO); Wet van 26 februari 1998, Stb. 1998, 161.

[5] Wet Toetsing levensbeëindiging op verzoek en hulp bij zelfdoding; Wet van 12 april 2001, Stb. 2001, 194.

Definition and characteristics

So far we have discussed several aspects of competence. As mentioned earlier, competence is an ethical concept, in the sense that it acts as a hinge between the values of autonomy and beneficence. Competence also is a presumption in the concept of informed consent, and it is a legal concept, in the sense that it represents a norm which authorizes persons to perform acts described by law. We have also explained that there is no clear definition available. However, during decades of discussion an attempt has been made to develop criteria to assess competence.

The core meaning of the concept has been described as the ability to perform a specific task (Beauchamp and Childress, 1994). In line with the etymological analysis of competence by Welie and Welie (2001), this presumes that the kind of task to be fulfilled is known, that it is known what it means to fulfil this task successfully, that the abilities needed to perform the task are known, and that it is known, that the person charged with the task has the required abilities.

The task to be performed can be described as making health care decisions, i.c. decisions about medical treatment or research. It is important to note that, according to this definition, competence is not a characteristic of a person. Competence is limited to the ability to make a specific decision (President's Commission, 1982; Berghmans, 2000). This means, in theory, that a person can be assessed as competent to make one decision, and at the same time be considered incompetent to make another decision. It also implies that *in*competence does not have a one-to-one relationship with illness, such as dementia, schizophrenia, or depression. Furthermore, competence can fluctuate in time: patients may be disturbed to a greater or lesser degree in their abilities to make decisions during certain periods, depending on the degree of severity of their illness.

The second issue concerns what it means to fulfil a task successfully, given the circumstances (Welie & Welie, 2001). This refers first of all to the criteria to assess whether or not a task has been performed well enough. Within the context of health care the assessment of competence has an 'all or none' character (Buchanan & Brock, 1989). In other words, competence is a 'threshold concept'. This means that either a person is able to perform the task well enough and might be considered to be 'competent', or a person does not succeed in performing the task well enough and will be considered to be incompetent. Associated with the threshold in the concept of competence is the discussion about the sliding scale concept of competence. The sliding scale concept implies that the threshold of competence should be higher in decisions which involve the risk of more severe consequences for the person in question, in contrast to decisions in a situation in which a person runs less risk of severe consequences (Drane, 1985; Buchanan & Brock, 1989; Wilks, 1997). Opponents of the sliding scale concept propose the use of a minimal threshold (Abernethy, 1984, 1991; Culver & Gert 1982, 1990; Wicclair, 1991; Buller, 2001). This implies that competence is being considered as an individual characteristic. A competency judgement is limited to the abilities of an individual, without considering the specific consequences of a specific treatment decision. Advantages of the minimal threshold above the sliding scale concept are: 1. the judgement of incompetence is independent of the judgement of respecting one's choice (no conflation); and 2. the competency judgement

is not asymmetrical. However, the sliding scale concept has the important advantage that persons are not being judged incompetent with respect to all decisions they may want to make. Being judged incompetent within the concept of the sliding scale means that the incompetency judgement is limited to a specific situation, providing that someone's autonomy is maximalized (Berghmans, 2000).

With regard to the abilities to perform the task well enough, many standards have been proposed. The fact that different terms like 'standards', 'capacities' and 'abilities' are used illustrates that the evaluative and descriptive aspects of the concept of competence overlap. The most influential standards have been developed by analysing jurisdiction on competence in the United States, which results in *legal* standards. Arguments used in legal judgements of competence have been transformed into standards of competence (compare Appelbaum & Roth, 1982; Appelbaum & Grisso, 1988; Roth, *et al.*, 1977). Consensus has been reached with regard to the following legal standards: the ability to understand, the ability to express a choice, the ability to manipulate information rationally, and the ability to appreciate the situation (Appelbaum & Roth, 1982; Appelbaum & Grisso, 1988; Roth *et al.* 1977). The standards represent a hierarchy of different levels of assessing competence. Depending on the risk/benefit ratio of the situation and the acceptance or refusal of treatment, one single standard is chosen to assess competence (Roth *et al.*, 1977). For example, when a decision does not have serious consequences for a person, a standard for expressing a choice or understanding is chosen. However, when a decision has serious consequences a person should be able to reason or to appreciate the situation in order to prove their competence. In the United States this development resulted in the above-mentioned sliding scale concept of competence.

With the development of instruments to assess competence, the combination of the different standards have started to lead their own life as an entirety of decision-making capacity, and not merely as legal standards. The standards were used to indicate decisional abilities, and instead of applying one standard depending on the situation, all abilities together formed one psychological construct of decision-making capacity (Appelbaum & Roth, 1982). By applying the psychological construct of decision-making capacity to a person, it is possible to assess whether the person charged with the task has the required abilities.

Relevance of competence of patients with cognitive decline or dementia

The prevalence of dementia in the Netherlands is 6.3% of persons 65 years of age and over, with a profound influence of age: the prevalence is almost 1% in persons aged 65, whereas it is 40% in persons over 85 years of age (Health Council of the Netherlands, 2002). In the Netherlands the absolute numbers of people with dementia are estimated to be 175,000 in 2002 and 207,000 in 2010 (Health Council of the Netherlands, 2002). It is also estimated that approximately 60,000 of the demented patients are institutionalized, half of them residing in homes for the elderly, and the rest in nursing homes (Health Council of the Netherlands, 2002). It may be assumed that nursing homes patients with dementia and their professional care-givers are often confronted with issues of competence concerning decisions about daily medical care. Recent evaluations of the Dutch health care law, in particular the WGBO, show that the autonomy of institutionalized elderly people seems to be compromised. In many situations, the patient's representatives are involved in health care decision-making, without taking the patient's opinion into consideration, or at least having made an assessment of the patient's competence (Hertogh, 2004).

In addition to questions concerning the competence of patients with cognitive decline and dementia to make treatment decisions, the question of competence also comes up in discussions on informed consent for the treatment of patients with psychiatric illnesses (Grisso *et al.*, 1997; Lapid *et al.*, 2003), patients with a chronic physical illness (Dekkers, 2001) or mentally disabled persons (Biesaart & Hubben, 1997; Cea & Fisher, 2003), and discussions on informed consent to participate in medical research (Carpenter *et al.*, 2000; Kim *et al.*, 2001), the legal status of the living will (Griffiths, 2002; Fazel *et al.*, 1999), and euthanasia requests from patients with dementia (Berghmans, 1999). The latter questions are beyond the scope of this thesis, which concentrates only on competence with regard to health care decisions made by elderly persons with and without cognitive decline and dementia. Nonetheless, these questions demonstrate a high societal interest in the concept of competence.

Summary and conclusion

In current literature, competence is conceptualized as decision-making capacity. Decision-making capacity primarily refers to cognitive abilities, and, as such, does not make explicit that competence can also be a normative statement about a person. It has been proposed that decision-making capacity should be distinguished from competence (Kim *et al.*, 2001). Decision-making capacity should be reserved to determine the cognitive abilities of the patient, as assessed by the physician. Competence should be restricted to the legal context in which a normative statement is made about a person. In the following of this thesis decision-making capacity will be used to refer to the cognitive abilities of a patient. Competence will be used to refer to a normative judgement, which incorporates the decisional capacities as well as the specific content and consequences of a treatment choice.

Patients with AD show a great variation in their levels of decision-making capacity. Some AD patients remain their decisional abilities, and others are impaired with a rather low standard of 'understanding', but have adequate decisional abilities on the higher standard of 'appreciation'. How can we explain this confusion? One explanation might be that differences in context (or circumstances) result in different levels of decision-making capacity. For example, differences in familiarity with treatment situations, in emotional factors, and in the levels of disability result in different levels of decision-making capacity. Apart from possible explanations however, such differences have to be taken into consideration when a physician assesses the competence of a patient. Clinical experience shows that demented patients may still have the ability to make decisions about their lives, even though they no longer avail of all the abilities that are summed up in the standards derived from the legal context. In such cases demented patients can no longer be considered as rational decision-making citizens, but it could be assumed that they have a *moral* capacity to make decisions which should be respected by care-givers.

In the following chapter we will discuss this issue of moral capacity. The philosophical considerations will result in an empirical framework, on the basis of which the aim of the thesis will be described. The (research) questions that will be answered in this thesis, the outline of the thesis and the methods will be described subsequently.

Knowing Well or Living Well: a Philosophical Introduction and Empirical Considerations

This chapter is a modified version of a paper that has been published as:
Van Leeuwen, E., & Vellinga, A. (2004). Knowing well or living well: is competence relevant to moral experience and capacity in clinical decision-making? In: Thomasma, D.C. & Weisstub, D.N. (eds.). *The variables of moral capacity*. Kluwer Academic Publishers, Dordrecht/Boston/London, 187-202.

Knowing well or living well: a philosophical introduction and an empirical framework.

In many western cultures, the law now requires that competent patients are allowed to make their own decisions in health-care. Incompetent patients need special protection and care, especially with regard to participation in medical research. In dealing with cognitively impaired, demented patients, however, clinical experience shows that these patients still can have the moral capacity to make decisions about their lives, at least within certain boundaries. These cases show that the concept of competence is based on socially accepted rules, variable among themselves in different situations. The physician has to balance the legal regulations with the moral interests of the patient. In this chapter the concepts of competence and moral capacity are discussed from a philosophical and an empirical point of view.

Generating philosophical hypotheses

Moral capacity and competence: overlapping human qualities?

Authors who write about competence acknowledge that it is impossible to give a clear definition of competence. Like Beauchamp and Childress, they admit that the individual perspectives of medicine, psychiatry, law, psychology, and philosophy have given the concept 'accumulated layers of meaning connected in diverse ways, but with different purposes and protective functions behind the various ideas' (Beauchamp & Childress, 1994: 133). However, this acknowledgement is frequently followed by some kind of general description, which is used as an instrumental definition serving the purpose of the argument. Beauchamp and Childress, for instance, confine themselves to what they see as the 'core meaning of competence': 'the ability to perform a task' (Beauchamp & Childress, 1994: 134). Chell takes another perspective by stating: 'Competency is essentially the ability to make a decision' (Chell, 1998). Both descriptions of meaning or essence omit the normative component that is essential in the assessment of competency in medicine and psychiatry. Beauchamp and Childress do so in order to restrict the normative component to the criteria of autonomy. In their view, 'Law, medicine, and to some extent philosophy presume a context in which the characteristics of the competent person are also the properties possessed by the autonomous person' (Beauchamp & Childress, 1994: 135). This presumption seems somewhat odd if we remember that the concept of competence has a much longer history than that of autonomy in law, medicine, and psychiatry. Apparently, Beauchamp and Childress argue in this way because they want autonomy to precede competence. This becomes clear when we look at the hypotheses they postulate, namely that an autonomous person is (necessarily) a competent person and that judgements of whether or not a person is competent should be based on whether or not the person is autonomous (Beauchamp & Childress, 1994: 135). The second hypothesis puts the cart before the horse, and directly makes the first hypothesis questionable. Later, Beauchamp and Childress even rebut both hypotheses by saying: 'Furthermore, for any person whose competency is in question, it seems disrespectful of autonomy to say….' (Beauchamp & Childress, 1994: 141). By using this phrase they acknowledge that the normative component of the concept of competence does not necessarily coincide with the normative component of the notion of autonomy. Appelbaum therefore rephrases a standard of competence that is also inextricably tied to the 'ideal of self-determination in modern Western societies,' but is drawn from a century long tradition of case law and statutory law in the Anglo-American World (Appelbaum, 1998).

What is startling is the way in which these authors deal with the normative component of the concept of competence and the ease they have in using dogmatic reasoning. The normative standard is either connected to an ideal, the autonomous person, or to a legal tradition of jurisprudence. The outcome of their reasoning does not differ essentially. Beauchamp and Childress define competence in a patient to make a decision 'if he or she has the capacity to understand the material information, to make a judgement about the information in the light of his or her values, to intend a certain outcome, and to freely communicate his or her wish to caregivers or investigators' (Beauchamp & Childress, 1994: 135). Appelbaum considers that the components of a standard of competence should be the following abilities: to express personal choice, to understand relevant information, to appreciate the significance of that information for the personal situation, and to reason with the relevant information so as to engage in a logical process of weighing options (Appelbaum & Grisso, 1988). The common outcome, regardless of the difference in the use of ethical or legal dogmatism, reveals what is at stake: the competent person has to be the citizen as presumed in the various theories of democracy and law in Western societies.

That citizen is considered to be a rational, decision-making individual who can be held responsible for his or her actions. The normative standard of competence expresses, furthermore, that probably not every human being within those societies will meet this standard, and those who do not are considered to be incompetent. They do not possess the essential abilities to be accepted as a citizen. Because of the dogmatic insertion of a connection with moral responsibility, they cannot be held morally responsible for their actions or choices.

All this may sound quite familiar and not at all surprising. However, in order to see what is below the self-evident surface, we have to ask ourselves what lies behind the dogmatic connection of the concept of citizenship and moral responsibility in legal and ethical discourse. In legal discourse the history of the meaning of competence is tied up with meanings of authority, qualification, discretion, license, jurisdiction, and so on. The roots of these ties go back to the protection of property, the authenticity of a will, the legal validity of a contract, the permission to get married, and so on. Such judgements of competence are social and legal decisions. They are normative in the sense of being speech-acts: they construct a social reality. So, whenever an adolescent reaches a certain age, sixteen or eighteen, he or she reaches the age of competent adulthood. Not because he/she has become an autonomous person or even a reasonable person – he/she might have been that for a long time or may never be so – but only because he/she has reached an age which is equal to the age of social maturity. At that age, one is accepted as a citizen and henceforth allowed to enter into contractual relationships, and so on. The determination of the specific age depends on historical and political contingencies of what is called social maturity. Furthermore, it is not unqualified. Being a competent person does not, for instance, imply that someone can drive a car: one needs a special license to do so. To call somebody legally competent is therefore a spoken act with a highly institutional character: it is a formal social act, resembling a 'rite de passage', giving permission to participate in social activities laid down by law.

Like every legal norm, the standard of competence also excludes people from social participation. The criteria for exclusion have to be based on factual evidence showing why someone is not able to participate in normal social activities and communications. Within legal discourse the exclusion will necessarily be based upon reasonable arguments derived from jurisprudence and statutory regulations. In the older days in Europe, for instance, such a criterion was established by the duty to pay tax, thereby excluding women, workers and wanderers. Nowadays we can find a similar criterion to exclude refugees, asylum seekers and 'guest-labourers'. We are only able to discover the historical and cultural settings of the criteria by examining who is excluded.

Exclusions based on racism, sexism, or sexual conduct have been prominent in most of the legal histories of Western countries corresponding with various religious and moral beliefs. The history of legal medicine and psychiatry is no exception in this respect, as Foucault and others have shown. In other words, the material conditions of competence and incompetence depend on the specific morality of a society. In the present Western societies this morality focuses mainly on cognitive and mental capacities, reflected in reasonable interests, choice-making, and rational deliberation. This focus postulates that someone who is rational will act accordingly, and that his actions will thereby result in what is morally and socially good. Although this focus may have a long history in philosophy and ethics, it is certainly not without problems or dispute.

An important origin of the focus upon reason when discussing what is morally good can be found in Plato's dialogues. In Protagoras and Gorgias we find Socrates arguing that

someone who does not make a mistake always has good intentions (Protagoras 345d-e), or that everybody always acts for the good (Gorgias, 467b). Rationality and reasonableness are similar in the quest for the good, while those who seek evil are either ignorant or insane, incompetent as we would say. This philosophical belief in a rational good man and a rational good society has, of course, not been without dispute. Even for Socrates, and for later philosophers, the dispute has been about the possibility of akrasia, or 'weakness of the will' (Peijnenburg, 1996). Perhaps St. Augustine formulated the human problem behind this weakness in the most pregnant terms. Speaking of his youth, he quotes himself: 'Give me chastity and continency, but do not give it yet' (Confessions VIII, vii). Weakness of the will means that someone knows what is best at the first, second and other levels of rational deliberation, but decides not to act accordingly, mainly because of other motives. Most people are familiar with this phenomenon of akrasia, and democratic freedom even allows us to yield to it in smoking, drinking, and other daily activities, as long as we do not harm others.

Still, the acceptance of the phenomenon does not force us to give up the idea that the pursuit of good is only made possible by accepting what is socially recognized as rational or reasonable. We almost have to stay with our ideas that this rationality alone makes us morally responsible beings, because otherwise we are at a loss in our social thinking as well as in our morality. Consequently, we have to accept the resulting paradoxes. For instance, a drunk driver who has been in an accident is considered to be legally and morally responsible for his actions, although we know that a crucial feature of being drunk lies in the fact that the person is no longer mentally capable of making rational decisions. Moral responsibility is then connected with the state of soberness that presumably preceded that of intoxication. This implies that we separate moral responsibility and competence. Being drunk implies a state of incompetence, but it does not relieve us from our moral responsibilities. The problem of akrasia thus tells us clearly from the time of Socrates to the present, that being mentally competent does not imply that our behaviour is morally responsible, yet moral responsibility can be maintained in situations of temporary incompetence.

While akrasia can make competent people act willingly in irresponsible ways, we also have to acknowledge that human beings who are considered to be incompetent can still act morally responsibly. We know that children can retain high morals in situations of stress, even when they themselves know that they are not competent to judge the situation (Kohlberg, 1984; Colby *et al.*, 1987). The fact that some Western countries, like the USA and the UK, have recently put children on trial in special cases, proves that we expect them to be able to act according to moral standards. We also know that mentally handicapped human beings who are suffering, for instance from Down's syndrome, are capable of making moral decisions about their future way of life. In other words: 'In practice, judgements of competency go beyond semantics or straightforward applications of legal rules; such judgements reflect social considerations and social biases as much as they reflect matters of law and medicine' (Roth *et al.*, 1977).

From these examples – and the list can be extended to patients in psychiatric wards, geriatric clinics, and so on – it becomes clear that by assessing competence we are making a normative distinction between two groups of people: the competent and the incompetent. Both groups may act morally responsibly or may, at some moment in time, fail to do so. Of course, we could continue by stating that competence therefore ought to be seen as a threshold (Buchanan & Brock, 1989: 18-20, Beauchamp & Childress, 1994: 136), but then we also have to admit that the distinction signifies a social norm by which we try to protect our ideal of good citizenship. Furthermore, restriction of the concept of competence to

cognitive and mental capacities tells us that we try to keep up a social norm of rational behaviour. The fact that this norm is connected to the concept of moral responsibility has, as such, nothing to do with the discriminating power of the norm, but mostly with the historical ideal that a good citizen is rational and will intentionally act with good intentions. We therefore postulate that competence and moral responsibility are overlapping human qualities; while the extent of the overlap depends upon the structure of a society and of social judgement.

Turning from a general analysis toward the specific area of treating the demented elderly, the social connection of cognitive functioning and moral responsibility strikes us as a paradox. Between care-giver and care-receiver a moral bond of respect for dignity and individual life-story is expected, while simultaneously the situation of cognitive impairment refutes this bond, replacing it by instrumental reasoning of what is considered by institutional practices to be the best. The result of this paradox is often that we treat demented persons as 'would be' persons, as if their mind is set for a long and perhaps final vacation. We talk with them as if they are morally responsible, but disregard what they say. If we accept the mutual implication of competence and autonomy, as Beauchamp and Childress suggest, then the only way out of this problem is to establish a practice of advanced directives. But, if we consider moral responsibility as only partly overlapping with cognitive competence, it becomes possible to discuss ways in which the features of cognitive impairment can be dealt with by care-givers and significant others. In order to demonstrate this possibility we postulate some elements derived from phenomenological thinking, especially the work of Alfred Schutz (Schutz & Luchman, 1974).

Following the later work of Husserl, Schutz has argued that each individual is uniquely structured by social norms, including morality in daily life. The uniqueness follows from the specific events that occur in the life world. The encounter with real life in the process of coping with the social norms and structures thus accounts for differences, even between identical twins. Within the life world we act and think in complex ways, combining memories, paradigmatic events, stories, emotions, and reflected experience. Part of our life we engage ourselves in institutional practices that are governed by rational thinking. As such, the problem of akrasia rises when we decide not to follow the rational directions of these institutions, but when we try to realize the hopes, ideals, or even illusions originating in the history of our lives, including that of parents, friends and beloved ones.

Apart from akrasia, other factors also play a role. Processes of remembering and forgetting, virtues and character also belong to what we usually call 'our self', as it depends upon what we are and how we came to be. In matters of morality, the distinction that is made between our personal life world and institutional thinking has a clear significance. When asked by a social institution, be it law or medicine, we have to recapitulate the pre-reflective complex morality that accompanies our acts. We rationalize according to the specific standards of our society in order to state specific facts, and by doing so we transgress the world of our personal beliefs and hopes and put them into reasons that are acceptable in public, institutional life. Moral capacity covers this ongoing process, resulting in a moral responsibility that is connected with the history of our selves.

In the case of cognitive impairment, the balance changes between public rational accountability and pre-reflective morality. The processes involved are still not exactly clear, but at least the ability to account for one's actions in rational or reasonable terms diminishes. Patients suffering from mild dementia are still able to make judgements of their own situations, which can be morally valuable, although they do not fit into the schemes of rational deliberation. If patients are still able to discuss relevant features of their lives, to tell parts of the history, to experience some form of self-awareness, and to enjoy meaningful relationships, we might postulate that they also have a sense of moral deliberation and responsibility, although they can be incompetent to participate in public life. In other words, someone who is unable to buy a ticket from a computerized machine or to find the way in the underground could still be morally responsible in discussions concerning family matters or possible treatments for somatic illness. On the other hand, someone who is still able to rationalize in public matters, may no longer be able to cope with the symptoms of a disease, repressing them in utter despair.

In order to sort these issues out, we need to carry out empirical research to find out if and how the rationalized medical account of disease and treatment is understood by the demented person and what role concepts such as meaning of life, self-awareness and meaningful relationships play in their world. In the following section we will translate these philosophical hypotheses into empirical considerations, which form the framework on which this thesis is based.

From philosophical hypotheses to empirical considerations

Based on the above considerations, we will search for a method that may empirically clarify the possible distinctions between moral capacity and competence. We have chosen to consider medical treatment. Do competent patients significantly differ in their deliberations from patients suffering from cognitive impairment when they have to decide to undergo an operation or an internal examination? If there are differences, do we ascribe them to differences in cognitive skills or to other factors, such as anxiety, depression, or the experienced meaning of life? These research questions will be addressed in an empirical study.

Competence and decision-making capacity

Several scales have been developed to assess decision-making capacity (Grisso & Appelbaum, 1991; Janofsky *et al.*, 1992; Martin & Glancy, 1994; Grisso *et al.*, 1997; Kitamura *et al.*, 1998). Most of these scales are based on legal standards: the ability to evidence a choice, the ability to understand, the ability to manipulate information rationally, and the ability to appreciate a situation. Not one of these methods is completely satisfying, because they all seem to reveal only a few aspects of the concept of competency or decision-making capacity. Yet, there are also researchers who have recommended a strictly individual assessment, mainly based on extensive psychiatric screening (Haekens, 1998). Because most assessment instruments are based on the legal standards, and presuppose that the relevant medical information has already been given to the patient, we have chosen one of these methods: the vignette method.

The clinical vignette has been used in various studies (Stanley *et al*, 1988; Sachs *et al*, 1994; Marson *et al*, 1995; Fazel *et al*., 1999). A vignette is a short story about a clinical (hypothetical) choice. The advantages and disadvantages of the choice are explained. The vignette is read aloud and is followed by some questions assessing the following abilities: evidencing a choice, understanding, reasoning, and appreciation of the situation. Although these questions also reflect the earlier mentioned legal standards, these abilities are not considered to be hierarchical, and are augmented with a question about the reason why the participant makes a certain choice. In other words, extra attention is paid to appreciation, which will also be reflected in the scoring of the vignette. Not only cognitively 'good' reasons or reasons mentioned in the vignette will be valued, but also (emotional) reasons in line with personal values. To avoid the possible danger that the vignette becomes strictly a memory test, the participants are allowed to obtain information from the vignette during questioning.

Since there has been much discussion about whether or not competence should be a sliding scale concept (Abernethy, 1984; Drane, 1985; see also page 13), we developed two different vignettes. The first vignette concerns a low-risk choice which we defined as performing gastroscopy or coloscopy in cases of anemia or fecal blood loss. The second vignette concerns a high-risk situation – a choice with life-threatening consequences – defined as whether or not to undergo surgery for colon carcinoma.

Vignettes in previous studies have always been presented as a hypothetical choice.[6] However, it can be argued that people respond differently to medical decision-making in real situations. In a real situation, the choice described in the vignette has really to be made, but in a hypothetical situation the participant is not suffering from the medical problem described in the vignette, so the choice is hypothetical. By distinguishing these aspects it is possible to compare the different external influences on decision-making capacity caused by the different circumstances.

Cognition and emotion

For a long time now the discussion on competence has been dominated by the influence of cognition and depression on decision-making capacity. However, during recent decades there has been widespread recognition that although mental illness does not invariably lead to decision-making incapacity, nevertheless a minimal level of rationality is required.

There have been some studies that have related certain aspects of cognition to level of decision-making capacity, as defined by the legal standards. Features that have been reported to correlate with loss of decision-making capacity are: word fluency, conceptualization, semantic memory, verbal recall, receptive aphasia and severe dysnomia (Marson *et al*, 1995; Marson *et al*, 1996). Although these cognitive functions are presumed to have a negative influence on decision-making capacity, it is not our aim to focus on the relationship between decision-making capacity and specific loss of cognitive functions. We do assume a certain relationship between cognition, decision-making capacity and moral capacity, but other factors might be equally relevant.

Several authors have acknowledged that too much attention has been paid to cognitive aspects in the assessment of decision-making capacity. Decisions are not taken in an emotional vacuum (Appelbaum *et al.*, 1981; Appelbaum & Grisso, 1988). Although the role of emotion or mood is acknowledged, the discussion usually concludes that, like declining cognition, emotion can only have a negative influence on competence or decision-making capacity. Consequently, depression is assumed to have a negative influence on competence (Haekens, 1998). Because of the assumed role of mood in decision-making capacity, this factor will also be measured in our research. The same assumptions have been made for the role of anxiety, which will be also taken into account. A positive role of emotion has only recently been mentioned by Charland (Charland, 1998; Charland, 1999). Emotion is approached by him 'cognitively', in accordance with the current emotion theories. In this approach, emotions become an essential ingredient of mental competence, when considering emotions as recognizable reasons and emotions as a basic for values and goals. This last assumption is further outlined in the next section.

[6] See for a more thorough analysis of this problem Chapter 5, which gives an overview of different instruments to assess decision-making capacity.

Meaning of life

In the wake of the statements issued by of the President's Commission, several authors have stressed the important role of a consistent pattern of goals and values in a competent person. These sets of values or 'conception of the good' (Buchanan & Brock, 1989) have only been described theoretically. The conviction of the importance of possessing a certain set of values has recently been supported by psychological theories on cognitive emotions. In these theories, emotions are assumed to form the basis of values and preferences. Emotions possess a conceptual evaluative dimension and involve appraisal. By the process of appraisal people are able to give personal meaning and significance to events and situations, and through this process they define and shape many of their goals and values, evaluating new situations, weighing up alternatives, and eventually making choices (Charland, 1999). Appraisal in this sense is to be distinguished from appreciation as one of the decisional abilities. Appreciation is defined as the ability to apply certain information to one's own situation (Grisso *et al.*, 1997). In addition to acknowledging the role of emotions in appreciation, it can also be postulated that emotions influence, for example, understanding of and reasoning about a particular situation. As emotions reveal the significance of events and situations to a person, they can also be presumed to play a role in the selection of information (Damasio, 1994). A recent empirical finding may support this thesis. In a study carried out by Cicirelli it became clear that elderly people do not make medical decisions by considering all the advantages and disadvantages of every new situation, but rather based on some sort of pattern of decision-making (Cicirelli, 1997). Here it can be presumed that some set or pattern of values has more importance in (medical) decision-making, than (a strictly cognitive) evaluation of the advantages and disadvantages.

Thus, there are several reasons to incorporate the concept of a set of moral and emotional values. One important reason is that the set of values may account for pre-reflexive personal meanings and values. In this way the (medical) decision-making capacity can probably be broadened to include moral capacity.

In the vignettes the question about why a certain choice has been made has been added to the questions concerning appreciation, in order to evaluate the personal meaning of the situation (described in the vignette) for the participant. Further on, apart from the vignette, we have operationalized the concept of a consistent set of goals and values as the concept of meaning of life. Meaning of life is defined as a set of more or less consistent values or convictions that an individual adheres to in thoughts and behaviour. In other words, a consistent set of values and goals in life can be translated as the content of the particular meaning of life of an individual. Literature on the concept of meaning of life and instruments developed to assess this concept can be found in psychology and psychopathology. In this study it seems reasonable to assess features of the concept of meaning of life, such as the level of the individually experienced set of values, or some general sense of meaning in life. Further on, attention will be paid to the content of this feeling. Two features, that are presumed to constitute a part of the meaning of life, will be considered in more detail: religion and attitude toward death.

Health, personality traits and social support

Other possible determinants in decision-making capacity include information about the health, some personality traits and the social support the participants experienced. These aspects can be assumed to influence the personal meaning and significance attached to certain situations. With regard to personality traits, in order to restrict the burden of the interview for the participants, we selected only those traits that most obviously play a role in decision-making.

Although there was a considerable amount of multi-pathology within our study population, we registered both objective and subjective health, to make it possible to compare the different groups. We assumed that subjective health would probably influence medical decision-making capacity.

Empirical research on the application of the concept of informed consent revealed several times that information given to somatic patients is not well understood and cannot be well remembered. It can be assumed that people either cannot understand medical information or that people have some kind of apathy for this kind of information. If this is so, it may be that individuals with a greater sense of competence or internal locus of control are more motivated and less apathetic to medical information and medical decision-making. Therefore, they may seem to be more competent in medical decision-making. The concept of mastery is also mentioned in the discussion about the competence of children. Developmental psychologists relate sense of internal locus of control to 'attentiveness to the decision'. Young children, who possess a more external locus of control, develop with age a more internal locus of control in their perception of the world. It is argued that children can only be competent once they have achieved an internal locus of control (Buchanan & Brock, 1989). Furthermore, both competence and locus of control are known to be influenced by somatic diseases and cognitive decline. As we also encountered these features, we hoped to obtain a broad understanding of the role they play in decision-making processes.

Finally, as is generally known, social support has significant associations with perceived well-being, anxiety, depression, etc. In this research the main focus will be on the perceived support and the satisfaction with this support. Perceived support can probably also be regarded as a motivational factor in medical decision-making.

The family

The literature does not give many clues for answers to the question with regard to the values a family attaches to decision-making and moral capacity. There are two central themes in the role of the family in decision-making situations. The first theme concerns the ethical discussion about who should decide and what should be decided for a patient who is considered to be incompetent. The differences between substituted judgement and best interest are outlined (Buchanan & Brock, 1989; Elliott & Elliott, 1991; Martyn, 1994). The second theme is investigated in an empirical approach to determine how families decide for an incompetent patient (Muncie *et al*, 1997; Zweibel & Cassel, 1989). The main conclusion that can be drawn from these investigations is that proxies make decisions that may by chance be related to the wishes of the patient. In other words, although the substituted choice is preferred, in reality little more can be achieved than a best interest decision. In line with these empirical findings are some research data which reveal that proxies have even more protective standards for their decision about the patient than they have for themselves and, above all, that they consider a patient to be incompetent earlier than professionals do (Biesaart & Hubben, 1997). The norms and values of proxies in their assessment of the decision-making capacity of a patient have not yet been described. In this research, interviews will be conducted with the family to investigate their opinions about the abilities of the patient, informed consent, the moral responsibilities of the physician, and their own moral responsibilities concerning the medical decisions made by and for the patient.

Physicians

The literature reveals that the assessments of competence made by physicians are inconsistent, and that they are most inconsistent in their assessment of patients with mild and moderate dementia (Marson *et al.*, 1997). Moreover, their experience does not seem to approve their ability to assess competence (Naglie *et al.*, 1993). Just like the family, the physician can also only make chance decisions about the presumed preferences of the patient and the actual preferences of the patient (Schneiderman *et al.*, 1997). Despite these empirical findings, very little attention has been paid to the values according to which physicians assess competence, and it is not known how they formulate their responsibility with regard to decisional situations and incompetent patients. To explore these issues, physicians will also be interviewed.

Conclusion

We generated hypotheses in a philosophical approach to the concept of competence. The discussion about competence in Western societies is profoundly influenced by various democratic and legal theories regarding citizenship. Competent persons are considered to be citizens with the capacity to make decisions and bear responsibility. The underlying morality postulates that someone who is able to think rationally will act accordingly, and that his or her actions will thereby be what is deemed to be morally or socially good. Still, the problem of akrasia, or weakness of will, shows that mental competence does not guarantee that a person will always act in a morally responsible and rational way.

On the other hand, we also argued that people who are considered to be *in*competent can still act morally responsibly. Therefore, from the moral point of view, the distinction between competence and incompetence reflects not so much a state of being, as a social norm according to which behaviour can be judged, but by relating competence to cognitive capacities, this social norm becomes a norm that focuses primarily on rational behaviour. We therefore postulated that competence and moral responsibility are overlapping human qualities, while the extent of overlap depends on the societal structure and social judgement. Within the context of mental and psycho-geriatric health-care it must then be clarified how cognitive impairment can affect competence, and furthermore to what extent moral responsibility can still be maintained. This need for clarification is evident in clinical practice, where demented elderly can sometimes act as morally responsible patients, while at the same time institutional practice forces us to consider them as incompetent patients.

By considering the possibility that moral responsibility partly overlaps with cognitive competence, it becomes necessary to reconsider theories of competence in the light of ability to act morally. Moral capacity can be defined as the capacity to make decisions based on an ongoing process to transgress the world of our personal history and beliefs into the moral standards of public institutional life.

We considered elements which may be connected to moral capacity. Elements hypothesized to be connected to the concept of moral capacity are: cognition and emotion, the meaning of life, health status, personality traits and social support, and the role of the family and physician. To link our hypotheses with existing scientific research we chose to refine a method used to assess decision-making capacity (the vignette method). In combination with the earlier described elements, we hope to develop further discussion about the issues of competence, decision-making capacity and moral capacity.

We conclude with the definitions of the various concepts mentioned in this chapter and the way they will be used in this thesis. Moral capacity can be defined as the capacity to make decisions based on an ongoing process to transgress the world of our personal history and beliefs into the moral standards of public institutional life. A more specific definition cannot be given as this concept is in development, and therefore also dependent on our findings. Competence will be used to refer to a normative judgement, which

incorporates the decisional capacities as well as the specific content and consequences of a treatment choice. Decision-making capacity will be used to refer to the cognitive abilities of a patient.

Aim and Outline

Aim and Outline

In developing philosophical thinking about competence and moral capacity, we argued that the concept of competence mainly plays a role at the level of institutional and legal thinking. Moral capacity, however, has a broader significance. It encompasses the way in which we structure ourselves during our life history, coping with institutional rules and norms. By investigating various aspects of this moral capacity in relation to decision-making capacity in medical situations, we hope to identify some of the basic elements of moral capacity. However, the first step is to examine the influence on decision-making capacity of factors that might contribute to moral capacity in elderly patients with cognitive problems. At the same time, in doing so we hope to develop a more refined method to assess decision-making capacity in elderly subjects. Because the empirical framework we sketched is too extensive to be tested in one thesis, we started modestly, using only the factors described in this chapter.

In this thesis the main emphasis is on the vignette method, which is a method to assess decision-making capacity. In empirical research the crucial point of discussion is the operationalization of the concepts that are being studied. In developing further thinking about competence and decision-making capacity, we wanted to investigate the influence of different circumstances in the assessment of decision-making capacity with the vignette method. Further, we focused on the influence of cognition as the most distinctive characteristic of patients with and without cognitive decline or dementia. These analyses are essential before investigating issues such as personality factors, social support and meaning of life, which have not been addressed in this thesis. Finally, we focused on the relationship between the assessment with the vignette method and competence judged by family members and physicians. These points of attention lead to the following outline of this thesis.

Chapter 4 describes the design and methods of the research, guided by the empirical framework mentioned in Chapter 2. Apart from a description of the study sample and the different questionnaires that we have used, the main focus is on the vignette, a method to assess decision-making capacity. By using this method to assess decision-making capacity under different test circumstances we have tried to refine philosophical thinking about competence, decision-making capacity and moral capacity.

Chapter 5 presents a review of the literature on methods to assess decision-making capacity. Various instruments have been developed in the field of psychiatry and psycho-geriatrics, and in this overview we analyse the characteristics of these instruments and investigate the differences between the instruments developed in these two fields. The conclusions reflect the validity of methods to assess decision-making capacity, and form a basis for the following empirical chapters.

In Chapters 6 and 7 we analyse the influence of the treatment choice on the decision-making capacity. The central question is: is the assessment of decision-making capacity affected by the content of treatment choice? In Chapter 6 two vignettes with a different content were tested in two groups of comparable elderly patients (with and without cognitive impairment). In Chapter 7 we investigate whether providing hypothetical or realistic information influences the assessment of decision-making capacity. By comparing the decisional capacity of both cognitively impaired and cognitively non-impaired patients in different treatment choice contexts, we can analyse the cognitive and emotional aspects of decisional capacity.

In Chapter 8 we analyse the relationship between decisional capacity and competency judgements by physicians and family members. In the absence of a gold standard for competence, we analyse the differences between decision-making capacity as assessed by

the vignette and the competency judgements made by family members and physicians. We analyse the degree of agreement between these judgements, as well as the associations of the three different judgements with patient characteristics (such as cognition, depression, physical functioning) and patient demographics. Hypotheses are generated about the factors underlying the differences between the different assessments.

In the General Discussion the results are examined in a broader context. After taking the methodological limitations of this study into consideration, we focus on some theoretical and societal implications. Do the results contribute to the proposed concept of moral capacity, and are, indeed, moral capacity and competence overlapping qualities?

The Summary is followed by an Appendix, which consists of a case-report. It describes the actual assessment of the competence of a psychiatric patient with somatic problems. We analyse the psychiatric arguments from a theoretical framework of competence, and this illustrates one of the major problems of assessing competence: the inter-relatedness of the assessment of the capacity of a patient and the consequences of the choice of the patient.

Chapters 5 till 8 have been written as separate articles. Therefore, each article can be read separately, but consequently the methodology sections overlap in these chapters. For reasons of consistency within this thesis, spelling and layout have been standardized. Consequently, the chapters may differ slightly from the original articles.

Design and Methods

Design and methods

This chapter describes the methodology underlying this thesis. First the sample and selection procedure of the sample are described, followed by a more detailed outline of the vignette method. Subsequently, the questionnaires used to assess the different patient characteristics are described in more detail. The variables that are described refer to the empirical considerations, presented in Chapter 2: Knowing well or living well. The data-collection resulted in a great variety of findings that could not be analysed within the scope of this thesis. Therefore, this chapter only discusses the questionnaires that were actually considered in this thesis.

Sample

The sample was selected from patients, 65 years of age and older, visiting geriatric wards for a one-day somatic and psychiatric screening. Only newly-admitted patients were included. Excluded were patients who were not able to participate in the interview, such as blind patients, patients who were not native (Dutch) speakers, and patients with severe dementia. Patients who had received the treatment described in the vignette (endoscopy) less than a year prior to the interview were also excluded, because they could have been biased by their actual experience.

Initially, the aim was to include 240 patients, subdivided into four groups: a hypothetical group consenting to undergo endoscopy, a hypothetical group consenting to undergo surgery for colon cancer, a realistic group offered endoscopy and a realistic group offered surgery for colon cancer.

A study of the incidence of anaemia and endoscopy in the participating geriatric ward revealed a lower incidence of anaemia and endoscopy than expected. In 1996 and 1997 the diagnosis of anaemia was reported respectively 32 and 35 times (in a total population of respectively 356 and 516 new patients each year). In 1998 the incidence of endoscopy was 38 (in a total population of 657 new patients). Because we wanted to include 60 patients in the realistic endoscopy group we decided to collect additional data from three other geriatric wards and a gastroenterology ward. During the data-collection we found it was difficult to collect data on realistic endoscopy situations and we found no patients who were actually undergoing surgery for colon cancer. Therefore the data-collection was amended to include patients in the realistic endoscopy situation and to exclude patients in the realistic situation of surgery for colon cancer.

A total of 245 patients were approached and invited to participate, 34 (14%) of whom refused to participate, 35 (14%) indicated that they were too ill or too tired, and 24 (10%) could not be interviewed due to logistical problems, such as lack of time during the one-day screening. Eventually, 152 patients were included, and these patients were subdivided into three groups. The first group consisted of 39 patients who were actually scheduled to undergo endoscopy. The remaining 113 patients were randomly divided into two groups. They were given a hypothetical treatment vignette, representing either endoscopy or an operation for colon cancer.

Most of the patients (n=139) were recruited in the Slotervaart Ziekenhuis, because this clinic has more geriatric patients (in 1998: 657 patients) than the other participating clinics. Our interview protocol was specifically developed for the logistical structure of this day-clinic. Especially those patients who were confronted with the realistic choice of undergoing endoscopy were selected in other wards (N=13). Table 1 *(see page 38)* shows the distribution of patients over the different hospitals, the different vignettes groups, and the distribution of the missing questionnaires among the 152 patients.

Physicians judged the patient's competence after they had discussed the results of the clinical investigations and the treatment options with the patient. Eventually, 124 judgements were collected from 35 different physicians; 28 judgements were missing due to logistical problems.

Family members who accompanied the patient to the hospital were interviewed before the physician discussed the treatment options with the patient. A total of 96 judgements made by family members were collected; 56 patients came alone to the ward.

Informed consent was obtained from all respondents: patients and family members. In some cases it may be questionable whether the patients could be considered competent enough to give informed consent for participation in this study. However, it would be

Table 1: Data acquisition: total number of patients recruited, the numbers of vignettes and clinimetric questionnaires acquired, and the number of competency assessments of family members and physicians.

	Total	Vignette A *hypothetical*	Vignette B *hypothetical*	Vignet A *realistic*
Hospital:				
- Slotervaart	139	60	47	32
- Other (MCA, Gooi-Noord, VU geriatrics, VU gastroenterology)	13	1	5	7
Vignette	152	61	52	39
MMSE > 16	142	56	49	37
GDS	151	61	52	38
ADL	126	52	45	29
IADL	133	56	47	30
Family members	96	38	36	22
Physicians (n=35)	124	50	44	30

impossible to include only patients who are competent, because a study of competence and incompetence can only be performed including patients with an arguable degree of competence (in order to contrast those who are competent with those who are incompetent). Our threshold for competence was low: a patient's consent was enough for participation. To avoid any possible harm, we tried to give patients as much information as possible about the study procedures, and provided an information folder. We also approached family members to obtain proxy consent, and stopped the procedure as soon as a patient seemed to be hindered by the interview. The study protocol was approved by the local Medical Ethics Committee, who agreed that our study could be qualified as a minimal harm study.

The vignette method

The vignette method I: the context of social psychological research

The vignette method was originally developed and used in sociological and experimental social psychological research. In general, this method has mainly been used to study normative beliefs. This technique can help to uncover the underlying collective preference schedules in order to unravel choice behaviour (Rossi, 1979).

A vignette consists of a short description of a person or a social situation, with precise references to what are thought to be the most important factors in the decision-making or judgement making processes of the respondents. The aim of this kind of questionnaire is to present a stimulus that is as concrete and as detailed as possible. Such a stimulus would more closely approximate a real-life decision-making or judgement making situation, than other, more abstract, questionnaires that are designed to determine human attitude or behaviour (Alexander & Becker, 1978). In this way the vignette method analyses people's judgements by systematically varying the characteristics used in the description of the

situation. The presumptions are that meanings are social and that morality may well be situation-specific (Finch, 1987).

The vignette method can be applied in several ways, mainly varying in the amount of different characteristics to which the respondent has to react. The common element in its various applications is its hypothetical character. It is argued that the object of study is not what the respondent actually would do under the presumed circumstances, but the publicly accessible morality (Finch, 1987). This hypothetical character ensures that the respondent reacts from his or her own situation, while at the same time the vignette describes a situation that is realistic and concrete enough to provoke a general normative reaction. However, this advantage is also the major disadvantage of the vignette method: what do the responses to the vignette tell us?

The vignette method II: the context of medical research.

The vignette method has also been used in medical research. It is important to underline the different meanings of the word 'vignette' in the field of medicine. Instead of a methodological technique to assess normative judgements or preferences, the word 'vignette' is also used as an alternative for the word 'case' or 'case-study'. In psychiatry, in particular, a vignette is used in this way. However, 'vignette' as a case-study is also used in reference to medical historical articles.

A vignette, as an instrument to assess attitudes as described above, can be applied in various ways. First, in medical decision-making analysis, the vignette is regularly used to assess patient preferences regarding health status/treatment alternatives. These analyses are performed to test utility theories, to investigate the determinants of patient preferences, or to study patient preferences with regard to their desire to participate in treatment decisions.

Secondly, the vignette technique can also be used to assess treatment decisions, made by physicians and nurses. In this respect, two themes can be distinguished. The first is characterized by emphasis on the competence of physicians or nurses with regard to medical technical decisions. A study of activities recommended by physicians for patients with chronic low back pain used three vignettes of work-disabled patients with chronic low back pain (Rainville *et al.*, 2000). It was concluded that the recommendations reflected personal attitudes of the physicians as well as factors related to the patients' clinical symptoms. The second theme is characterized by emphasis on normative characteristics of health care workers. For example, Green et al. (2000) studied several circumstances under which medical residents were likely to deceive a colleague. In another study the physician's willingness to deceive third party payers was assessed (Freeman *et al.* 1999). In psychiatry the vignette has been used to investigate the thoughts, beliefs and expectations of the general population with regard to patients with certain mental disorders. Specific attention has been paid to the stigmatization of mental disorders, such as schizophrenia, and its relationship with dangerous behaviour (Link *et al.*, 1999; Penn *et al.*, 1999).

The vignette method III: the context of competency judgements[7]

The aim of the vignette used to assess decision-making capacity is fundamentally different to that in the previously described research. Instead of unravelling normative beliefs, the aim of this method is to test decision-making abilities. Consequently, the respondent is

[7] A more thorough introduction of different methods to assess decision-making capacity is given in Chapter 5.

confronted with only one vignette instead of several vignettes describing different characteristics of a particular situation. The vignette describes the nature of a disease, as well as the nature of the treatment alternatives and their advantages and disadvantages. A similarity with the vignette methods used in sociological research is the hypothetical character of the presented treatment choice. Subsequently, the emphasis in the questions that are asked after the vignette has been read, focuses on decision-making abilities: the ability to evidence a choice, the ability to understand facts, the ability to manipulate information rationally, and the ability to appreciate the nature of the situation.

The vignette method IV: the Amsterdam vignette study

The method to assess decision-making capacity which is evaluated in this thesis was developed in an earlier study (Gouwenberg *et al.,* 1997; Schmand *et al.*, 1999), the aim of which was to evaluate the reliability and validity of a vignette method to assess decision-making capacity in elderly people with cognitive impairment. In this population-based study, 240 elderly people (64 of whom were demented) were questioned on the basis of five vignettes, two representing a hypothetical treatment situation, and three representing a research situation.

It was concluded that the reliability of the vignette method was satisfactory (Cronbach's alphas of .76 and .80).

Validity was tested by correlating the vignette scores to both the physician's judgement and to scales representing the level of cognitive impairment. The correlation between the physician's judgement and the vignette scores was reasonably high (treatment vignette: r = .65 and research vignette: r = .60). This means that the correlation was high enough to conclude that the vignette scores and the physician's judgement concerned the same characteristic. It was also low enough to conclude that the vignette scores were additional to the physician's judgement, because they differed (Gouwenberg *et al.*, 1997).

Decision-making capacity was found to decrease significantly with increasing severity of the dementia, and associations were found between decision-making capacity and several cognitive functions. Cognitive functions that best explained decision-making capacity were recent memory, expressive language, and abstract thinking (Schmand *et al.*, 1999). Further, decision-making capacity was only slightly correlated with education and verbal intelligence, which implies that the vignette method is relatively unbiased with respect to education (Schmand *et al.,* 1999).

A multidisciplinary expert panel was questioned about the vignette in order to test its face validity. This panel consisted of 154 experts and included people with a legal background, psychologists, psychiatrists, geriatricians, general practitioners, people with an ethical background, nurses, nursing home physicians and elderly people. Many members of this expert panel stated that they had been confronted with the assessment of competence (70.8%), and that an instrument to assist such an assessment would be helpful (86%). The vignette method was considered by most of them to be a useful instrument (74%). No differences were found between the opinions of people with different backgrounds (Gouwenberg *et al.*, 1997).

Overall it was concluded that the vignette method can be a useful method to assess decision-making capacity in the elderly persons (Gouwenberg *et al.*, 1997; Schmand *et al.*, 1999).

The vignette method V: the context of this thesis

The content of the vignette used in this study was determined in collaboration with experienced geriatricians and psychiatrists. The content of the vignette should reflect a rather common treatment choice, which would also be experienced as a choice. In general, the opportunity to have a blood test, for example, does not represent a choice for most people. We presumed that the need for a choice is clear when there are serious advantages and disadvantages involved, which should be weighed up before a choice can be made. In collaboration with the specialists, the choice of endoscopy in the case of unknown blood loss was considered to be suitable for this purpose.

We wanted to compare the same choice in both a hypothetical and a realistic situation. Therefore the choice of treatment in the vignette should reflect a choice with an adequate incidence. A literature search showed that anaemia related to gastro-intestinal disease is a problem with a high incidence in an elderly population (Joosten *et al.*, 1992; Pentimone *et al.*, 1992). The vignettes describe the choice to undergo endoscopy for anaemia with an unknown cause (Box I), and the choice to undergo an operation for colon cancer (Box II).

After the vignette had been read, the participants were asked questions to assess their decision-making capacity. Their abilities were based on the following standards: factual understanding, evidencing a choice, reasoning, and appreciation of the situation. During the reading and the interview, the participants were allowed to read the vignette. Answers to the questions were scored as follows: 0 points for no answer or an incorrect answer, 1 point for a more or less satisfying answer, and 2 points for a satisfying answer (Box III).

Inter-rater reliability

To examine inter-rater reliability, the vignettes of 45 participants were rated by a research assistant and one of the authors (AV). Kappa was computed for the total vignette score, which was divided into tertiles for this purpose. Reliability results (kappa = 0.64) for the total vignette score reflect a good inter-rater agreement (Altman, 1999).

Cognition and emotion

Cognition was operationalized in two different ways. The diagnosis of dementia was made according to DSM-IV criteria (DSM-IV, 1994). Further, a global impression of cognitive functioning was acquired with the Mini-Mental State Examination (MMSE) (Folstein *et al.*, 1975). The MMSE consists of 20 items, with scores ranging from 0-30, higher scores indicating better cognitive functioning. The sum-score consists of the following elements: orientation in time and place, memory, attention, language and visual construction.

Emotion was converted in two concepts: depression and anxiety. Depression was assessed with the Geriatric Depression Scale (GDS) (Brink *et al*. 1982) (Dutch translation: Kok, 1994). The GDS has a yes-no format and contains less somatic items than other depression scales. Both aspects reduce bias in an older population (due respectively to cognitive or concentration problems and somatic complaints). The scale consists of 30 items, higher scores indicating more depression.

Health

Physical functioning was operationalized in three different ways. First, the number of chronic diseases was registered. These were dichotomised in no disease or one disease, and two or more diseases. Secondly, activities of daily living (ADL) were registered with the Barthel index, with scores ranging from 0-20. Higher scores indicate a higher level of functioning in daily activities such as eating or dressing (Mahoney & Barthel, 1965). Thirdly, the instrumental activities of daily life (IADL) were registered with the Fillenbaum index, with scores ranging from 0-14. Higher scores indicate a lower level of functioning in IADL such as making a phone call or shopping (Fillenbaum, 1985).

Judgements of physicians and family members.

The physicians and family members made a dichotomous judgement of competence: competent or incompetent. The physicians were given no instructions for the assessment of competence, in order to reflect the assessments made in daily practice as much as possible. It was explained to family members that nowadays patients have the right to make their own medical decisions, but that one of the conditions is that the patients are competent to make these decisions. The ability to make medical decisions may, for instance, be influenced by a deteriorating health status (somatic or cognitive). Subsequently, the family members were asked whether they thought that the patient was able to make a medical decision or not. The type of relationship between the family members and the patient and the frequency of contact were registered, as well as the following demographic characteristics: gender, age, and total years of education.

Box 1:

Vignette A – Endoscopy

Let's assume you have anaemia. This could be caused by a stomach disorder. Your doctor has suggested that he or she can carry out an examination to find the cause. During this examination the doctor will pass a tube containing a small camera down your throat and into your stomach. You are free to decide whether or not you want to undergo this examination. Whatever your decision, you will still receive treatment for your anaemia.

One benefit of this examination is that it often reveals the cause of the blood loss. The most common cause is a gastric ulcer, which is not particularly serious and can easily be treated by medication. This is therefore an effective treatment for the underlying cause of the blood loss.

However, it is sometimes necessary to remove a small piece of tissue from the stomach, for a detailed examination. This does not hurt. The tissue is examined in the laboratory. There is a slight chance that it will show that you have stomach cancer. The doctor will give you the results of these laboratory tests several weeks after your examination, when he or she will also explain how the results of these tests will affect you.

One drawback of this examination is that it does involve a degree of discomfort. The stomach can only be examined when it's empty. Starting on the evening of the day before your examination, you must eat nothing until the examination has been completed. During the examination, a small tube (containing a camera) will be put into your mouth, down your throat and into your stomach. At the beginning, you will have to actively swallow the front end of this tube. During the examination itself, which takes about 10-30 minutes, you will be lying on your side. This procedure very seldom causes any complications.

The advantage of not undergoing the examination is that you can avoid the associated discomfort, but the disadvantage is that the cause of the blood loss remains unknown. This means that a possible stomach ulcer or stomach cancer will remain untreated. Also, the bleeding may continue, which means that the anaemia will take longer to cure.

Box II:

Vignette B – Surgery for colon cancer

Let's assume you have cancer of the intestine. The doctor has just explained what this means, and has asked you to decide whether or not you wish to have treatment.

The most common form of treatment involves surgery. The extent and duration of the operation will depend on the size of the tumour itself. The aim of this operation is to cure your cancer. The size of the tumour is important too, because this affects the chances of the operation being successful.

Depending on where the tumour is, it may be necessary to make an ostomy. This is an artificial opening in the skin of your belly. Faeces are drained from the body through this opening and into a small bag. Several months after the first operation, another operation can be carried out to remove the ostomy and join the ends of the intestine up again. Other forms of treatment may subsequently be required, but this will be discussed with you after the operation.

It will take you some time to recover from this operation. At first, you may have some problems with diarrhoea, but this will pass in time. You may also feel tired for some considerable time, either as a result of the cancer or the treatment.

You are also free to refuse the treatment. This would spare you the burden of undergoing surgery, but it would probably shorten your life.

Box III:

Standards of decision-making capacity

Ratings as follows:
- *2 = adequate*
- *1 = partially adequate*
- *0 = inadequate*

<u>Understanding (0-6)</u>
- *Can you tell me something about your disease? (0-2)*
- *Can you tell me something about the proposed treatment? (0-2)*
- *Can you mention some advantages and disadvantages of the treatment? (0-2)*

<u>Evidencing a choice (0-2)</u>
- *Can you say whether or not you want to be treated?*

<u>Reasoning (0-8)</u>
- *Can you give some reasons why you (don't) want to be treated?*
  - *(0-2) patient mentions consequences of treatment*
  - *(0-2) patient compares treatment alternatives*
  - *(0-2) patient mentions consequences in addition to those mentioned in the vignette*
  - *(0-2) patient's choice logically follows from his or her own explanations*

<u>Appreciation (0-4)</u>
- *What kind of effect does your choice have on your health?*
- *How does this situation affect you and your family?*
  - *(0-2) patient acknowledges that the described treatment affects him/her*
  - *(0-2) patient acknowledges the treatment's potential benefits*

Resulting in a total score: 0-20

Instruments to Assess Decision-making Capacity: An Overview

Vellinga, A., Smit, J.H., van Leeuwen, E., van Tilburg, W., & Jonker, C. (2004) International Psychogeriatrics, 16, 397-419.

Instruments to assess decision-making capacity: an overview

The main objective of this article is to evaluate and describe instruments for assessing decision-making capacity in psychiatry and psycho-geriatrics, and to evaluate them for use in daily practice. The instruments were selected in Medline articles. We focus on the relationship between these instruments and the concept of competence, represented in the following elements: context in which an instrument is developed, disclosure of information, standards to assess decision-making capacity, the scale or threshold model, and validity and reliability. The developmental context influences how information is provided and standards defined. Although it is not clear how decision-making capacity relates to competency judgements, most instruments provide good reliability. Comparison of the different instruments opens directions for future research. Although instruments can never replace a physician's judgement, they may provide a clear starting point for a discussion on competence. In daily practice assessments, attention should be given to information disclosure, the influence of our own normative values in evaluating standards of decision-making capacity, and the relation between decision-making capacity and competence.

Introduction

Competence is a complex concept with ethical, legal, social, and psychological dimensions (Glass, 1997). Assessment of competence is an issue in many disciplines: psychiatry, psycho-geriatrics, ethics, and law. This article deals only with questions of competence regarding consent to treatment and consent to scientific research programs.

Studies suggest that physicians find it difficult to assess decision-making capacity in older adults and psychiatric patients, and to distinguish between mental status examinations and competency assessments (Fitten *et al.*, 1990; Kitamura & Kitamura, 2000). Moreover, experienced clinicians frequently disagree on their competency assessments for patients with Alzheimer's disease (Marson *et al.*, 1997). Many instruments have been developed to provide a more objective standard for these assessments.

The aim of this article is to categorize existing instruments. We selected articles containing reports of instruments through Medline searches using the keywords: 'competence,' 'decision-making capacity,' and 'informed consent,' in combination with 'instruments.' Instruments were identified by reviewing references in these articles. The central selection criterion was the description of an instrument to assess competence in consent to treatment or research. Excluded was literature on competence or decision-making capacity of children and mentally disabled persons (Cea & Fisher, 2003), as well as literature on legal capacities such as financial capacity (Marson *et al.*, 2000b), capacity to choose a place of residence, draw up a will, assign power of attorney (Rutman & Silberfeld, 1992; Silberfeld, 1994), execute a healthcare proxy (Mezey *et al.*, 2000), or to stand trial (Hoge *et al.*, 1997). Also excluded was literature on instruments to assess general mental competence (Wang & Ennis, 1986; Alexander, 1988).

The term competence was defined as decision-making capacity in the instruments (Drane, 1984; Buchanan & Brock, 1989), and it will only be used to refer to legal or ethical dimensions (see also Kim *et al.*, 2001). The instruments were developed in two contexts: psychiatry and psycho-geriatrics. The characteristics of the instruments are evaluated by contrasting these (medical) contexts. Legal perspectives on instruments were not examined.

Situation specific character

Decision-making capacity is specific to a particular decision (President's Commission, 1982). This is expressed in instruments by focusing on a specific decision. Three different types of decisions were recognized: 1) decision-making capacity to consent to treatment decisions, 2) decision-making capacity to consent to participate in research, and 3) decision-making capacity to execute an advance directive.

Assessing decision-making capacity in psychiatry

Table 1 shows that a major concern in psychiatry is decision-making capacity to consent to treatment. Some instruments specifically focus on consent to voluntary admission by newly-admitted psychiatric patients (Appelbaum *et al.*, 1981; Appelbaum *et al.*, 1998; Kitamura *et al*, 1998). These instruments are applied to a general psychiatric population. Other instruments focus on the decision to undergo electroconvulsive treatment (Bean *et al.*, 1994; Martin & Glancy, 1994) or on patients diagnosed with psychosis, schizophrenia, or major depression (Grisso & Appelbaum, 1991; Grisso *et al.*, 1997; Appelbaum *et al.*, 1999; Carpenter *et al.*, 2000; Palmer *et al.*, 2002; Lapid *et al.*, 2003).

Table 1: Assessing decision-making capacity in psychiatry[8]

Study	Instrument	Population	Decision	Content	Structure
Appelbaum (1981)	Questionnaire	50 psychiatric patient	voluntary admission	realistic (not provided)	non-structured
Grisso (1991)	MUD	26 pat schizophrenia	treatment	realistic + hypothetical	structured
		25 pat depression			
		26 pat ischemic heart dis			
		25 outpat. (controls)			
Bean (1994)	CIS	96 patients ECT	treatment (ECT)	realistic	non-structured
Martin (1994)	ECT questionnaire	-	treatment (ECT)	realistic (not provided)	non-structured
Grisso (1995b, 1995c)	UTD	75 pat schizophrenia	treatment	realistic	structured
	POD	92 pat major depression		realistic	
	TRAT	82 pat ischemic heart dis		hypothetical vignette	
	EC	3 groups control pat		hypothetical vignette	
Grisso (1997)	MacCAT-T	40 pat schizophrenia	treatment	realistic	semi-structured
		40 controls			
Appelbaum (1998)	MUD-VH	100 psychiatric pat	voluntary hospitalization	realistic	structured
Kitamura (1998)	SICIATRI	25 psychiatric pat	(voluntary) admission	realistic	semi-structured
		23 med. ward pat			
Appelbaum (1999)	MacCAT-CR	26 pat. depression	research	realistic	structured
Carpenter (2000)	MacCAT –CR	30 pat schizophrenia	research	hypothetical	structured
		24 controls			
Moser (2002)	MacCAT-CR	25 pat schizophrenia	researchs	hypothetical	structured
		25 pat HIV positive			
Palmer (2002)	MacCAT-T	16 pat psychotic dis.	treatment	realistic	semi-structured
	HCAT				
Saks (2002)	CSA	27 outpatients psychosis	research	hypothetical	structured
		12 inpatients psychosis			
		15 controls			
Lapid (2003)	MacCAT-T	40 pat depression	treatment: ECT	realistic	semi-structured

Assessing decision-making capacity in psycho-geriatrics

Within psycho-geriatrics instruments show more variation in types of decisions. Table 2 shows most instruments focus on decision-making capacity to consent to participate in research, whereas others assess decision-making capacity to consent to treatment or write advance directives (also: Molloy *et al.*, 1996). The elderly are perceived as vulnerable with regard to competence (Stanley *et al.*, 1984), especially nursing home residents (Fitten *et al.*, 1990) or hospitalized elderly (Fitten & Waite, 1990). Among the elderly, there is also special attention to those with major depression (Stanley *et al.*, 1988), patients with Parkinson's disease and cognitive impairment (Dymek *et al.*, 2001), and patients with Alzheimer's disease or dementia (Stanley *et al.*, 1988; Sachs *et al*, 1994; Marson *et al.*, 1995a, 1995b; Fazel *et al.*, 1999; Schmand *et al.*, 1999; Kim *et al.*, 2001; Kim *et al.*, 2002).

Information disclosure

The concept of informed consent requires that patients be given relevant information about a treatment before their consent can be considered valid (Meisel *et al.*, 1977; Beauchamp & Childress, 1994). To fulfill this, all instruments include information about the purpose and nature of the treatment (or research procedure), its risks and benefits, and alternative treatments. Information is given in either a hypothetical or realistic manner, which influences the structure of the disclosure.

Information disclosure in psychiatry

Table 1 reveals that psychiatric instruments mainly provide information about realistic decisions. The information is disclosed in a semi-structured way, enabling a situation specific assessment. Information is presumed to be provided in everyday practice (Appelbaum *et al.*, 1981) or as part of the instrument (Grisso & Appelbaum, 1991; Grisso *et al.*, 1997; Appelbaum *et al.*, 1998; Appelbaum *et al.*, 1999).

For example: the MacCAT-T guides clinicians and patients through a process of information disclosure, assessing patients' capacity for decision-making (Grisso *et al.*, 1997). Before the interview the clinician selects relevant information by reviewing the patient's symptoms, diagnosis, and treatment needs from the hospital chart. This information is recorded in appropriate sections of the MacCAT-T form and is disclosed at the beginning of the interview. Similarly, the Disclosure Content Check List is used to check the relationship between information given to the patient and the way the patient uses and reflects this information (Kitamura *et al.*, 1998).

Information disclosure in psycho-geriatrics

Table 2 shows that psychogeriatric information generally centers on hypothetical decisions disclosed in a standardized way. The term 'vignette' is used for this format (Fitten *et al.*, 1990). A vignette provides a hypothetical description of a situation (treatment or research),

[8] Abbreviations used in this table: CIS = Competency Interview Schedule; CSA = California Scale of Appreciation; EC = Expressing a Choice; ECT = Electro Convulsive Therapy; HCAT = Hopkins Competency Assessment Test; MacCAT-CR = MacArthur Competency Assessment Tool – Clinical Research; MacCAT-T = MacArthur Competency Assessment Tool – Treatment; MUD = Measuring Understanding Disclosure; POD = Perceptions of Disorder; SICIATRI = Structured Interview for Competency and Incompetency Assessment Testing and Ranking Inventory ; TRAT = Thinking Rationally About Treatment ; UTD = Understanding Treatment Disclosures.

Table 2: Assessing decision-making capacity in psycho-geriatrics [9]

Study	Instrument	Population	Decision	Content	Structure
Stanley (1984)	research projects descriptions	39 elderly pat 41 young pat	research	hypothetical	structured
Stanley (1988)	consent form description	38 pat dementia 45 pat depression 20 elderly controls	treatment	realistic	structured
Fitten (1990)	clinical vignettes	51 nursing home pat 15 elderly controls	treatment	hypothetical	structured
Fitten & Waite (1990)	clinical vignettes	25 medical pat (age>60) 25 elderly controls	treatment	hypothetical	structured
Janofsky (1992)	HCAT	25 psychiatric patients 16 medical inpatients	informed consent	realistic (about informed consent procedure)	structured
Marson (1995b)	CCTI (vignettes)	29 pat Alzh. dis. 15 elderly controls	treatment	hypothetical	structured
Sachs (1995)	research vignettes	42 pat Alzh. dis. 64 proxies	research	hypothetical	structured
Barton (1996)	HCAT	44 nursing home pat	informed consent advance directive	realistic (about informed consent procedure)	structured
Etchells (1999)	ACE	100 inpatients	treatment	realistic	semi-structured
Fazel (1999)	Vignettes	50 pat dementia 50 elderly controls	advance directives	hypothetical	structured
Schmand (1999)	clin. and research vignettes	64 pat dementia 119 elderly controls	research and treatment	hypothetical	structured
Dymek (2001)	CCTI (vignettes)	20 Parkinson's dis. cogn. imp. pat 20 elderly controls	treatment	hypothetical	structured
Kim (2001)	MacCAT- CRV	37 pat Alzh. dis. 15 elderly controls	research	hypothetical	structured
Kim (2002)	MacCAT-CRV	37 pat Alzh. dis. 15 elderly controls	research	hypothetical	structured

including elements such as the nature of a disease, recommended treatment, and its risks and benefits. Vignettes, presented to subjects on a sheet of paper and read aloud by the examiner, are used to assess decision-making capacity for consent to treatment, participation in research, and writing advanced directives. During the interview subjects are permitted to consult the written text or sections are reread to the subjects if necessary (Fitten & Waite, 1990, Schmand *et al.*, 1999; Dymek *et al.*, 2001).

Realistic or hypothetical situations?

The effect of hypothetical or realistic information disclosure on the assessment of decision-making capacity is unclear. One study considered the effects of presenting information realistically and hypothetically (Grisso & Appelbaum, 1991). The Measuring Understanding Disclosure (MUD) consists of four standardized disclosures about treatment recommendations for schizophrenia, depression, ischemic heart disease, and deep venous thrombosis. The disclosures were presented to groups of patients with schizophrenia, depression, or ischemic heart disease, and to a healthy control group. The study evaluated the differences in understanding information related and unrelated to the participant's own disorder. Patients understood information related to their own disease better than hypothetical information.

Disclosure of realistic information is preferred within psychiatry. Appelbaum argued that standardized methods to assess competence are appropriate for research, but not for clinical use (Appelbaum, 1997). This is confirmed by Kitamura et al., who argue that no two patients have the same illness characteristics or are recommended exactly the same treatment (Kitamura *et al.*, 1998). The patient's understanding and rational manipulation of medical information, however, are functions of the quality and quantity of the information given prior to testing. A predetermined set of information may achieve better validity and reliability for the measuring instrument (Kitamura *et al.*, 1998).

Within psycho-geriatrics it is argued that vignettes can satisfactorily approximate real physician-patient assessment situations (Marson *et al.*, 1995b). Concrete vignettes are more useful than general questions for eliciting patients' values or research preferences (Sachs *et al.*, 1994). However, it is also acknowledged that deciding about a real, personal medical problem is different from decision-making in a hypothetical medical situation (Marson *et al.*, 1999; Dymek *et al.*, 2001; Kim *et al.*, 2002). Because advance directives consider hypothetical future situations by definition, the hypothetical character of vignettes is very similar in concept.

Assessing decision-making capacity: standards

After information is disclosed, decision-making capacity is tested through several questions representing different standards derived from the legal concept of competence. Consensus has been established on the following standards:

a) ability to evidence choice,
b) ability to make a reasonable outcome of choice,
c) ability to understand information,
d) ability to manipulate information rationally,
e) ability to appreciate the situation and its consequences (Roth *et al.*, 1977; Appelbaum & Roth, 1982).

[9] Abbreviations used in this table: ACE = Aid to Capacity Evaluation; CCTI = Capacity to Consent to Treatment Instrument; HCAT = Hopkins Competency Assessment Test; MacCAT-CRV = MacArthur Competency Assessment Tool – Clinical Research Version.

Table 3: Standards used in psychiatric instruments

Author	Instrument	Standards of competence	Scoring range	Cutoff
Appelbaum (1981)	Questionnaire	min. required clinical criteria broad clinical criteria legal criteria clinical-legal criteria	0-30	- (scale)
Grisso (1991)	MUD	understanding	0-10	- (scale)
Bean (1994)	CIS	evidencing choice understanding issues related to treatment manipulating information rationally and giving rational reason for treatment decision appreciation of the nature of the situation and its consequences (feeling of voluntarism)	4 x (1-7) 3 x (1-7) 2 x (1-7) 5 x (1-7) 1 x (1-7)	- (scale)
Martin (1994)	ECT questionnaire	evidencing choice factual understanding manipulate info rationally appreciation		
Grisso (1995c)	UTD POD TRAT EC	paraphrased recall and recognition nonacknowledgment of disorder (NOD) nonacknowledgment of treatment potential (NOT) seeking information (deleted in TRAT 2) consequential thinking comparative thinking complex thinking generating consequences weighting consequences (deleted in TRAT-2) transitive thinking probalistic thinking	0-10 0-2 0-2 0-2 0-2 0-2 0-3 0-3 0-3 0-2	
Grisso (1997)	MacCAT-T	understanding reasoning appreciation evidencing choice	0-6 0-8 0-4 0-2	- (scale)
Kitamura (1998)	SICIARTI	awareness of being informed evidencing choice does not waive understanding wants to get better insight		level 0 level 1 level 2 level 3 level 4
Appelbaum (1998)	MUD-VH	understanding	0-4	scale

Table 3: *Standards used in psychiatric instruments*

Author	*Instrument*	*Standards of competence*	*Scoring range*	*Cutoff*
Appelbaum (1999)	MacCAT-CR	understanding appreciation reasoning evidencing choice	0-26 0-6 0-8 0-2	
Carpenter (2000)	MacCAT-CR	understanding appreciation reasoning evidencing choice	0-6 (0-26) 0-6 0-8 0-2	- (scale)
Moser (2002)	MacCAT-CR	understanding appreciation reasoning evidencing choice	0-26 0-6 0-8 0-2	(scale)
	evaluation to sign consent	understanding		cutoff
Palmer (2002)	MacCAT-T	understanding appreciation reasoning ability to communicate choice	0-6 0-4 0-8 0-2	scale
	HCAT	understanding durable power of attorney	0-10	scale
Saks (2002)	CSA	appreciation: patently false belief standard	0-36	scale
Lapid (2003)	MacCAT-T	understanding relevant information reasoning about potential risks and benefits appreciation of the nature of the situation and consequences of alternative choices ability to express choice.	0-6 0-8 0-4 0-2	scale
Palmer (2002)	MacCAT-T	understanding appreciation reasoning ability to communicate choice	0-6 0-4 0-8 0-2	scale
	HCAT	understanding durable power of attorney	0-10	scale
Saks (2002)	CSA	appreciation: patently false belief standard	0-36	scale
Lapid (2003)	MacCAT-T	understanding relevant information reasoning about potential risks and benefits appreciation of the nature of the situation and consequences of alternative choices ability to express choice.	0-6 0-8 0-4 0-2	scale

Table 4: Standards used in psychogeriatric instruments

Author	Instrument	Standards of competence	Scoring range	Cutoff
Stanley (1984)	research vignettes	reasonable outcome	consistency with degree risks/benefits	- (scale)
		quality of reasoning	1-7	
		comprehension	1-4	
Stanley (1988)	capacity assessment (vignette)	comprehension	1-4	-
		quality of reasoning	1-5	(scale)
Fitten (1990)	clinical vignettes	understanding	0-3 (1 / vignet)	(< 3 and < 2)
		choice		
		reasoning		
Fitten & Waite (1990)	clinical vignettes	understanding (procedure, purpose,risk/benefits)	3 x (0-2)	99.5% confidence limit of controls
		reasoning	0-2	
Janofsky (1992)	HCAT	understanding	0-10 (6 Q)	incompetent < 4 sensitivity ~forensic psychiatrist
Sachs (1994)	research vignettes	willingness to participate	-	-
		reasoning	(qualitative analysis)	
Marson (1995a)	CCTI (vignettes)	evidencing choice	categorical scale	< 2 SD of the mean in a control group for each standard.
		reasonable outcome	categorical scale	
		appreciation	interval scale	
		provide rational reasons	interval scale	
		understanding	interval scale	
Etchells (1999)	ACE	understanding	Yes, unsure, no	definitely incapable, probably incapable, probably capable, definitely capable.
		appreciation		
		evidencing choice		
Fazel (1999)	Vignettes	understanding	0-4	incompetent < 6
		evidencing choice	0-2	
		provide rational reasons	0-1	
		appreciation	0-3	
Schmand (1999)	research and treatment vignettes	evidencing choice	?	< 95% control group
		understanding		
		manipulate info rationally		
		appreciation		
Dymek (2001)	CCTI (vignettes)	evidencing choice	0-4	4 = capable, 3 = marginally capable, 0-2 = incapable
		reasonable choice	0-1	1 = capable, 0 = incapable
		appreciating consequences		capable > 1.5 SD below control mean
		providing rational reasons		marginally capable 1.5-2.5 SD control mean
		understanding		incapable < 2.5 SD below control mean
Kim (2001, 2002)	MacCAT-CRV	understanding	0-26	sensitivity/specificity, gold standard:
		appreciation	0-6	expert clinical judgement (cut offs
		reasoning	0-8	respectively: 18,5,6)
		evidencing choice	0-2	incapable if patients failed any of the three standards (2002)

As no specific patterns were discovered in the standards for either context, the meaning of standards was evaluated for both contexts (tables 3 and 4).

a) Evidencing choice

Evidencing choice means that a patient either consents to or refuses medical treatment or research participation. This standard focuses on the presence or absence of a decision (Roth *et al.*, 1977). Although it has been argued that consistency of choice in time is important, this aspect is not considered in the instruments.

Within the psychiatric context this standard is part of most instruments (Appelbaum *et al.*, 1981; Bean *et al.*, 1994; Martin & Glancy, 1994; Grisso *et al.*, 1997; Kitamura *et al.*, 1998; Appelbaum *et al.*, 1999; Carpenter *et al.*, 2000; Moser *et al.*, 2002; Palmer *et al.*, 2002; Lapid *et al.*, 2003). Several studies confirm that this standard requires fewest demands on patients' abilities. Psychiatric patients were fully capable of expressing choice about a treatment decision, and were as able as control groups to evidence choice (Kitamura *et al.*, 1998; Grisso & Appelbaum, 1995b; Grisso *et al.*, 1997). Patients with recurrent major depression were also able to communicate choice about consent to participate in research (Appelbaum *et al.*, 1999). Although not statistically significant, patients with schizophrenia performed slightly worse than the control group on this aspect (Carpenter *et al.*, 2000; Moser *et al.*, 2002).

Evidencing choice is also included for the instruments in the psychogeriatric context (Marson *et al.*, 1995b; Schmand *et al.*, 1999; Dymek *et al.*, 2001; Kim *et al.*, 2001). This standard was met by 60-69% of patients with dementia (Sachs *et al.*, 1994). Other studies showed that even patients with mild or moderate Alzheimer's disease retained the capacity to elect choices about treatment and research participation (Marson *et al.*, 1995b; Kim *et al.*, 2001). Patients with Parkinson's disease, however, performed significantly worse on this standard than controls (Dymek *et al.*, 2001).

b) Reasonable outcome

This standard emphasizes decisional outcome rather than how a decision has been reached (Roth *et al.*, 1977), but it has been severely criticized because mainstream consensus on reasonableness can become an important factor in suppressing personal autonomy. Despite the criticism, it has been integrated in several instruments in the psychogeriatric context (Stanley *et al.*, 1984; Sachs *et al.*, 1994; Marson *et al.*, 1995b).

Reasonable outcome is defined in instruments as willingness to participate in medical research (Stanley *et al.*, 1984; Sachs *et al.*, 1994). 'Reasonable' has been defined as a low degree of willingness to participate in research with a high risk/benefit ratio, and a high degree of willingness to participate in research with a low risk/benefit ratio (Stanley *et al.*, 1984). The elderly and patients with Alzheimer's disease were able to reach reasonable decisions to the same degree as younger patients or proxies (Stanley *et al.*, 1984; Sachs *et al.*, 1994; Dymek *et al.*, 2001). Also Kim et al. (Kim *et al.*, 2002) found no differences in willingness to participate in research between subjects with Alzheimer´s disease and control subjects. However, another study suggested that with increasing cognitive impairment, elderly individuals tended to opt for treatment interventions (Fazel *et al.*, 2000). One study defines reasonable outcome as a congruence between decisions by patients and decisions by 'reasonable' people. Patients with mild or moderate Alzheimer's or Parkinson's disease showed no differences from a control group on this standard (Marson *et al.*, 1995b; Dymek *et al.*, 2001).

c) Factual understanding

The ability of understanding requires that individuals understand relevant information. Although general ability to understand has been proposed as a standard to assess competence (Roth *et al.*, 1977), most instruments use factual understanding as their standard (Roth *et al.*, 1977; Appelbaum & Roth, 1982). Relevant elements are: the proposed treatment, its risks and benefits, and the possibilities of alternative treatment (Stanley *et al.*, 1984; Stanley *et al*, 1988; Fitten *et al.*, 1990, Fitten & Waite, 1990; Grisso & Appelbaum, 1991; Bean *et al.*, 1994; Martin & Glancy, 1994; Marson *et al.*, 1995b; Grisso *et al.*, 1997; Kitamura *et al.*, 1998; Etchells *et al.*, 1999; Schmand *et al.*, 1999; Carpenter *et al.*, 2000; Palmer *et al.*, 2002; Lapid *et al.*, 2003). Psychiatry augments these with issues like comprehension of the reason or purpose of admission to a psychiatric ward (Appelbaum *et al.*, 1981, 1998), or patient comprehension of the right to decide (Kitamura *et al.*, 1998). Psycho-geriatrics sometimes considers only the nature of the informed consent procedure (Janofsky *et al.*, 1992).

Factual understanding for schizophrenic patients was significantly compromised (Grisso & Appelbaum, 1995b). They also performed worse than medically ill patients, HIV positive patients, and patients with depression (Grisso & Appelbaum, 1991; Grisso *et al.*, 1997; Carpenter *et al.*, 2000; Moser *et al.*, 2002). Patients with depression perform quite well: 90% obtained full credit on most items of the understanding scale (Appelbaum *et al.*, 1999). Another study, however, revealed that depressed patients performed worse than a healthy control group, although there were no differences between them and a group of patients with angina (Grisso & Appelbaum, 1995b).

Within psycho-geriatrics older patients (mean age 69) showed significantly less understanding than younger ones (mean age 34) (Stanley *et al.*, 1984), which was not explained by differences in intelligence, years of education, or level of attention (Fitten *et al.*, 1990). Scores for the depressed elderly were similar to those of the control group (Stanley *et al.*, 1988). Hospitalized elderly, cognitively impaired patients, patients with mild or moderate Alzheimer's disease, and patients with Parkinson's disease demonstrated poorer performance in understanding (Stanley *et al.*, 1988; Fitten & Waite, 1990; Marson *et al.*, 1995b; Dymek *et al.*, 2001; Kim *et al.*, 2001).

Understanding does not depend exclusively on patients' abilities, but also on the extent of information disclosed by physicians. Data showed that psychiatric patients generally received less information than medical in-patients (Kitamura *et al.*, 1998). Moreover, both psychiatric and medical patients performed better when the information was disclosed in several units, with the appropriate question following each unit (Grisso & Appelbaum, 1991). Also, education about the recommended treatment or the research proposal influences the level of understanding (Wirshing *et al.*, 1998; Carpenter *et al.*, 2000; Dunn *et al.*, 2002; Lapid *et al.*, 2003). Therefore, assessing understanding in relation to giving information seems reasonable (Appelbaum & Grisso, 1995; Kitamura *et al.*, 1998).

d) Manipulating information rationally

The standard of manipulating information rationally relates to using logical processes to compare benefits and risks for various treatment options (Appelbaum & Grisso, 1988). Although requiring logical consistency between conclusions and starting premises seems straightforward, it can pose considerable practical problems. It is difficult to distinguish between rational and irrational reasons (Roth *et al.*, 1977; Kitamura *et al.*, 1998). The process of logical manipulation should be central, not the rationality of a decision's outcome.

Within psychiatry manipulating information rationally is related to concern for personal well-being, desire to recover, and hope for future recovery (Bean *et al.*, 1994; Martin &

Glancy, 1994). Other researchers determine this through questions examining the patient's explanations for his or her choices: whether the patient mentions consequences of treatment alternatives, compares alternatives, expresses thoughts about consequences besides those offered in the disclosure, and whether the final choice logically follows from the patient's explanation (Grisso *et al.*, 1997). Patients with schizophrenia have a significantly lower mean score than control groups (Grisso & Appelbaum, 1995b; Grisso *et al.*, 1997; Carpenter *et al.*, 2000). Patients with major depression perform worse than control groups on reasoning measures as well (Grisso & Appelbaum, 1995b; Appelbaum *et al.*, 1999), although depressed patients' reasoning improved after education (Lapid *et al.*, 2003)

Psycho-geriatrics defines the standard of rational manipulation of information as the capacity to use logical processes to compare risks and benefits of treatment options and to weigh this information to reach a decision (Stanley *et al.*, 1988). Patients with Alzheimer's disease and cognitively impaired patients with Parkinson´s disease performed worse on this standard than cognitively non-impaired elderly controls (Marson *et al.*, 1995b; Dymek *et al.*, 2001; Kim *et al.*, 2001). Hospitalized patients were not found to perform worse than healthy controls (Fitten & Waite, 1990). Interestingly, Stanley et al. found that while depressed and cognitively impaired elderly subjects did not differ from the control group, the quality of reasoning is not very high in all three groups (Stanley *et al.*, 1988). They did not weigh thoroughly risks and benefits (Stanley *et al.*, 1988), which may accord with the finding that both demented patients and elderly controls give similar reasons to participate in research (Sachs *et al.*, 1994). Also Marson et al. (Marson *et al.*, 1995a) suggested that rational reasoning depends more on general reasoning ability than on reasoning based on specific factual recall.

e) Appreciation

The standard of appreciation emphasizes the consideration of facts relevant to an individual's situation. Because appreciation requires an element of self awareness, it differs from rational manipulation, in which information must merely be weighed (Appelbaum & Roth, 1982).

Appreciation in psychiatry centers on questions that determine whether a patient acknowledges that information is personally applicable and the treatment beneficial (Grisso *et al*, 1995c, 1997). Other elements include: awareness of illness, need for treatment, and the doctor's role (Bean *et al.,* 1994; Martin & Glancy, 1994). The California Scale of Appreciation focuses on the concept of 'patently false belief' (Saks *et al.,* 2002). Adequate appreciation summary ratings were obtained from more than 80% of schizophrenic patients; 10% had low ratings (Grisso *et al*., 1997). Other studies revealed that schizophrenic patients scored significantly lower than comparison groups (healthy, or patients with depression or angina, or HIV positive patients) (Grisso & Appelbaum, 1995b; Carpenter *et al.*, 2000; Moser *et al.*, 2002). Like factual understanding, appreciation improved after an educational program (Carpenter *et al.*, 2000).

A small subgroup of patients with depression performed poorly on the appreciation scale. Patients with prior research experience obtained full credit, whereas only one-half of the patients without this experience obtained full credit on the appreciation scale (Appelbaum *et al.*, 1999). Another study found that although patients with depression acknowledged their illness as readily as patients with angina, they were significantly less likely to acknowledge the value of treatment (Grisso & Appelbaum, 1995b). Appreciation of depressed patients also improved after education (Lapid *et al.,* 2003).

Appreciation has been defined in psycho-geriatrics as the capacity to evaluate the emotional and cognitive consequences of treatment choice. This standard emphasizes

patient awareness of the consequences of a treatment decision: its emotional impact, rational requirements, and future consequences (Marson, 1994). A control subgroup performed significantly better on appreciation than patients with Alzheimer's disease: over 60% of those with moderate Alzheimer's disease and 33% with mild Alzheimer's were marginally competent or incompetent (Marson *et al.*, 1995b). This finding was recently confirmed (Kim *et al.*, 2001). Patients with Parkinson's disease were also found to perform significantly worse on appreciation than a control group (Dymek *et al.*, 2001).

Determining competence: scale or threshold?

The ongoing discussion about whether to operationalize competence as a threshold or gradual model reflects the difference between decision-making capacity and competence. While decision-making capacity is a matter of shades of difference (gradual model), competence is either present or not (threshold model) (Buchanan & Brock, 1989). Although a gradual model may be more consistent with clinical practice, a definitive judgement on competence is often required in a particular situation. The question is: how are decision-making capacity and competence related?

Within psychiatry most instruments were designed to be scored using a scale (table 3) (Appelbaum *et al.*, 1981; Bean *et al.*, 1994; Grisso *et al.*, 1995; Palmer *et al.*, 2002). Each standard of decision-making capacity, usually defined as the sum of the different abilities, is scored separately, although it is argued that the scores of different abilities should not be added (Grisso *et al.*, 1997; Palmer *et al.*, 2002). One study described a cut-off based on scores two standard deviations below the mean score of all subjects (Grisso & Appelbaum, 1995a).

Table 4 shows that most psychogeriatric instruments use a separate scoring system for each ability, although one threshold is determined for most instruments. Fitten et al. chose to use passing two of three vignettes as the threshold (Fitten *et al.*, 1990). Others based thresholds on statistical arguments. Incompetence has been defined as two standard deviations below the mean score in the control group (Marson *et al.*, 1995b; Dymek *et al.*, 2001), or scoring below the fifth centime of the control group (Schmand *et al.*, 1999). The threshold of competence is also regarded a normative judgement, which should be determined by experts (see also Fazel, 1999). Other methods to determine a cut-off were based on raters' judgements, test-retest study results, and correlation with another competency instrument (Fazel *et al.*, 1999).

Validity and reliability

Different forms of validity have been discussed for assessing decision-making capacity: face-validity, construct validity, and content validity. Face-validity is demonstrated by the focus in instruments on a treatment choice (Fitten *et al.*, 1990). Further, the abilities being assessed should relate closely to appropriate (legal) standards of competence (Appelbaum & Grisso, 1995). Most instruments use standards equal to the legal construct of competence (see tables 3 and 4).

Several studies found the construct validity satisfactory (Fitten *et al.*, 1990; Fazel *et al.*, 1999; Schmand *et al.*, 1999) because of the high correlations between decision-making capacity instruments (Fazel *et al.*, 1999), between decision-making capacity and other variables (e.g., cognitive screening tests) (Fitten *et al.*, 1990), and between decision-making capacity and dementia severity and physicians' judgements of competence (Bean *et al.*, 1994; Schmand *et al.*, 1999).

In medicine sensitivity and specificity characterize an extra dimension of validity. Determining these aspects of decision-making capacity and competence is difficult, because

there is no gold standard, but using expert judgements (e.g., old age or forensic psychiatrists) is one way to address the issue (Fazel *et al.*, 1999). Based on sensitivity and specificity, a specific test determines competence better than brief mental screenings.

Reliability is expressed in inter-rater reliability and test-retest reliability. Table 5 shows many studies have reported inter-rater reliability (e.g., research interviewers or psychiatrists). Fazel et al. reported raters' findings (geriatric psychiatrists) correlated highly with each other (r = 0.94) and also with the interviewer (r = 0.95) (Fazel *et al.*, 1999). Etchells et al. correlated judgements of experts, clinicians, and research nurses (Etchells *et al.*, 1999). Table 5 shows inter-rater reliability is satisfactory in all studies, both for different subscales and the total scale.

Table 5: Reliability of instruments assessing decision-making capacity

Authors (year of publication)	Instrument	Inter-rater reliability
Stanley (1988)	research vignettes	.87 quality of reasoning .97 comprehension
Janofsky (1992)	HCAT	.95
Bean (1994)	CIS	.95
Marson (1995a)	CCTI (vignettes)	R > .83 (LS3-LS5) > 96 % agreement (LS1 and LS2)
Grisso (1995c)	UTD TRAT	Kappa: >.84 (subtests) Kappa > .85
Grisso (1997)	Mac-CAT	.99 understanding .87 appreciation .97 evidencing a choice
Etchells (1999)	ACE	experts: agreement 82% Kappa 0.63 clinician/research nurse: agreement 93%, Kappa 0.79 SMMSE/experts: 0.89 agreement
Fazel (1999)	vignettes	.94 and .95
Carpenter (2000)	MacCAT-CR	.52 choice .98 understanding .84 reasoning .84 appreciation
Kim (2001)	MacCAT-CRV	.94 understanding .90 appreciation .80 reasoning
Palmer (2002)	MacCAT-T	.85 understanding .87 appreciation .75 reasoning
Saks (2002)	CSA	.85 appreciation (patients)

Test-retest reliability is only reported in three studies (Bean *et al.*, 1994; Grisso *et al.*, 1995; Fazel *et al.*, 1999). Moderate consistency in test-retest reliability was found in a mentally healthy control group (Fazel *et al.*, 1999). Within a group of psychiatric patients, Pearson correlations computed separately for each item between 0.43 to 0.98 (Bean *et al.*, 1994). Grisso et al. reported low consistency in the mentally ill groups, which may be explained by changes in psychiatric status. These findings support the idea that decision-making capacity is influenced by relatively stable cognitive abilities, but is sensitive to changes in mental status (Grisso *et al.*, 1995).

For practical applicability, an instrument should be performed easily and not be very lengthy. Most studies find satisfying inter-rater reliability, which suggests that a method to assess decision-making capacity can easily be learned by non-specialists. Further, it was found that when experienced physicians were guided by standards of decision-making capacity, there was more agreement (Marson *et al.*, 2000a). Administrating the instrument and assessment takes approximately 15-20 minutes (Janofsky *et al.*, 1992; Grisso *et al.*, 1997; Etchells *et al.*, 1999; Fazel *et al.*, 1999), which seems appropriate in light of the consequences of a competency assessment.

Discussion

An instrument's clinical value is largely determined by its validity, which depends on the relationship between concept and the characteristics of a measuring instrument. The discussion of clinical value will therefore reconsider some conceptual issues of instrument characteristics.

The question of competence arises in specific situations, and is reflected in the central position of decisions within the instruments. Our analysis shows that instruments were developed within specific patient populations. While similar words are used to describe decision-making capacity in psychiatry and psycho-geriatrics, there are several important differences. Differences exist in the way information is provided (hypothetical or realistic) and in the definition of standards used.

All studies considered stress the importance of providing relevant information before assessing decision-making capacity. The effects of providing hypothetical or actual information on assessing decision-making capacity are unknown. Although a specific choice is given in the (hypothetical) vignettes, the question of competence arises for situations different from the hypothetical one. Competence in one situation does not imply competence in another, which throws doubt on the value of information from hypothetical instruments. Nevertheless, hypothetical situations are similar to clinical ones, and do provide insight into a patient's ability to make clinical decisions.

The past three decades have seen many discussions on standards to assess competence. Although the standards have a legal origin, they are now used for assessing abilities to make decisions. One effect of this is that decision-making is perceived as a process, and reasonableness of choice is no longer accepted as a standard for competence; the internal logical structure of reasons is more important than rationality of reasons. Nevertheless, the content dependent character of rational manipulation of information cannot be totally denied. While it is true that reasonableness of choice should not determine assessment of competence, we should not make judgements without being aware of our normative values about rational argumentation or appropriate appreciation.

Perhaps the standards of competence (and decision-making capacities) overemphasize the cognitive side, as emotion plays a role in decision-making (Charland, 1998; 1999). Modern emotion theory views emotions as containing basic values and goals, which are important in making competent decisions (President's Commission, 1982; Buchanan & Brock, 1989). Emotions may make a difference in assessing decision-making capacity in hypothetical or realistic situations. Although discussed, the empirical grounds for the role of emotion in assessing decision-making capacity have not been studied.

There is a need to reconsider the relationship between the different standards, the presumed hierarchy (criticized in Grisso & Appelbaum, 1995a), and the relation between standards and competence. Should the different standards be considered separately, even though they may overlap in important ways? If it is possible to distinguish different decisional abilities, what is their relation to competence? One recent study on the relation between decision-making capacity and competence stressed the importance of distinguishing between a clinical impression of decision-making capacity (as a scale) and dichotomous judgement of competence, which should also take into account the risk and benefits of the specific situation (Kim *et al.*, 2001). Instruments cannot replace the judgement of a physician, they can only provide an approximation of decision-making capacity. Because assessment of competence is normative, a statistical solution is not satisfactory.

The above discussion focused on issues that may influence the validity of instruments. While most instruments provide a more reliable assessment than physicians' judgements that do not use instruments, future research should focus on enhancing the validity of such instruments. They can be improved by: 1) testing a single instrument on different populations; 2) evaluating the effect of providing hypothetical or realistic information; 3) reconsidering the definition and use of standards by reexamining the emphasis on cognition and our normativity in assessing them; and 4) reconsidering the relation between decision-making capacity and competence.

Finally, competency assessments in clinical practice cannot wait for future discussions because we need to know how to judge competence now. We need to consider first the situation specific character of competence. Decision-making capacity can only be determined after the patient is provided with relevant information. Education may also improve decision-making capacity. Equally important, there is more or less consensus on standards: ability to evidence choice, to understand relevant information, to manipulate information rationally, and to appreciate a situation. These standards may provide insight into a patient's decision-making capacity. Final judgement on competence should take into account the overemphasis on cognition, the evaluator's normativity, and an evaluation of the risks and benefits of the specific situation (Kim *et al.*, 2001; Palmer *et al.*, 2002). Instruments that address these features may provide a starting point for discovering a good trade-off between personal autonomy and well being.

Treatment Situation influences Decision-making Capacity of Cognitively Impaired Persons

An earlier version of this chapter was published in Dutch:
Vellinga, A., Smit, J.H., van Leeuwen, E., van Tilburg, W., & Jonker, C (2002). De beoordeling van ouderen met en zonder cognitieve stoornissen: de vignetmethode nader bekeken. Tijdschrift voor Gerontologie en Geriatrie, 33: 207-211.

Treatment situation influences decision-making capacity of cognitively impaired persons

This article focuses on decision-making capacity of elderly persons (n = 105) both with and without cognitive impairment (MMSE ≥ 16) in two treatment situations differing in severity of health consequences. Decision-making capacity was assessed with two clinical vignettes, representing respectively a hypothetical treatment situation with severe consequences (operation for colon cancer) and mild consequences (endoscopy). The following abilities were evaluated: evidencing a choice, understanding, reasoning and appreciating a situation. In general the vignette with severe consequences was better understood than the vignette with mild consequences. In the vignette with mild consequences elderly persons with cognitive impairment performed significantly worse on understanding, reasoning and appreciation than elderly persons without cognitive impairment. In the vignette with severe consequences elderly persons with cognitive impairment performed significantly worse only on understanding as compared to elderly persons without cognitive impairment. Decision-making capacity is less limited by cognitive impairment when assessed in a treatment situation with severe consequences. When circumstantial factors affect the assessment, the use of hypothetical vignettes should be reconsidered. Assessing decision-making capacity in realistic situations can adjust more for the complexity and consequences of a particular decision in which the question about an individual's decision-making capacity emerges.

Introduction

Within psycho-geriatrics clinical vignettes have been proposed to facilitate assessments of decision-making capacity (Stanley *et al.*, 1988; Fitten *et al.*, 1990; Sachs *et al.*, 1994; Marson *et al.,* 1995b; Schmand *et al.*, 1999; Kim *et al.,* 2002). Vignettes describe a particular hypothetical medical situation. Relevant information is provided to enable a person to consent to a specific medical treatment or research procedure. Several abilities are evaluated to assess decision-making capacity: the ability to evidence a choice, to understand, to reason, and to appreciate a situation. Evidence is found that elderly persons with cognitive impairment perform worse on these abilities than elderly controls without cognitive impairment (Sachs *et al.*, 1994; Marson *et al.*, 1995a, 1995b; Schmand *et al.*, 1999).

The situation specific character of competence stresses that a person may be competent or incompetent depending on the situation, which may differ in terms of complexity and severity of consequences (President's Commission, 1982; Appelbaum & Grisso, 1995; Lowe *et al.*, 2000). In this respect complexity refers to the requirements posed to decisional abilities of a subject. It has been argued as well that the severity of consequences of a particular choice should be used to determine the threshold of competence. According to the sliding scale model more serious consequences of a particular decision require higher standards of competence, resulting in higher requirements for a treatment refusal than for treatment consent (Drane, 1985; Buchanan & Brock, 1989).

Thus far few studies have evaluated the effect of different situations on decision-making capacity. In these studies severity of consequences was expressed in risk/benefit ratios of hypothetical research protocols (Stanley *et al.*, 1984; Sachs *et al.,* 1994; Kim *et al.*, 2002). In comparison to elderly persons without cognitive impairment, elderly with cognitive impairment were equally able to make reasonable decisions about research participation, even though their comprehension was diminished (Sachs *et al.*, 1994). Fitten suggested that the higher the complexity (defined in this study as more risks than benefits), the higher the percentage of elderly with cognitive impairment who would fail on decision-making capacity, which was only partly confirmed (Fitten *et al.*, 1990). Unfortunately, no relation has been studied between the complexity of a treatment situation, its consequences, and standards of understanding, reasoning, and appreciation.

This article focuses on the assessment of decision-making capacity in two different hypothetical treatment situations. We formulated the following question: "In what way is decision-making capacity of elderly patients with and without cognitive impairment influenced by treatment situations differing in degree of severity of consequences?" We distinguish a situation with mild consequences, the choice whether or not to undergo an endoscopy, from a situation with severe consequences, the choice of whether or not to undergo an operation for colon carcinoma. In line with the theoretical concepts and the empirical findings we expect that a situation with severe consequences will require more of a person's abilities – and therefore be more complex – to exhibit a competent choice, especially of patients with cognitive impairment. This will have consequences for the use of hypothetical vignettes to assess decision-making capacity in clinical practice.

Methods

Study sample

The study group was selected among patients, aged 65 +, visiting geriatric wards for a somatic and psychiatric screening (July 1999 to December 2000). Inclusion was based on newly-admitted patients. Men were approached first, as men are underrepresented in this geriatric population.

Excluded were patients who were not able to participate in the interview: blind patients, patients who were no native speakers, and patients with severe dementia. Patients who obtained the treatment described in the vignette within one year before our interview were excluded as well. Their performance on competence may differ from other patients, because their actual experience may interact with the hypothetical character of the vignette. For the same reason patients with a serious chance for a proposal for a gastro-or colonoscopy were excluded from this study. However, this group was interviewed with a vignette about their actual situation (Vellinga *et al.*, 2005, see also Chapter 7).

A total of 245 patients were approached to participate. Of this population 34 (14%) refused to participate, 35 (14%) indicated they felt too ill or exhausted, 10 (4%) had a MMSE score lower than 16, and 24 (10%) could not be interviewed due to organisational problems. Eventually, 142 patients were included, of which 37 patients had been proposed an endoscopy in reality.

This study focuses on the remaining 105 patients. They were randomly divided in two groups. One group was confronted with a hypothetical vignette with mild consequences, the other was confronted with a hypothetical vignette with severe consequences.

Approval for this study was given by the local medical ethics committee. Written consent was obtained from all participants.

Interview procedure

Interviews were performed by the researcher (physician, first author), research nurses, and psychologists. They were thoroughly trained, especially in recognising and coping with the possible confusion that may be caused by confronting cognitively impaired patients with hypothetical situations. Interviews were audio taped in order to monitor the quality of the data collection.

Decision-making capacity: the vignette method

Decision-making capacity was assessed with a clinical vignette. The structure of the vignettes is in line with earlier described vignettes (Sachs *et al.*, 1994; Schmand *et al.*, 1999). The subject and content of the vignettes were developed in collaboration with experienced geriatricians and psychiatrists.

Vignette A describes a situation with mild consequences, namely the choice of undergoing an endoscopy for anaemia with unknown cause (box I). Vignette B describes a situation with severe consequences, namely the choice of undergoing an operation for colon cancer (box II). This vignette was regarded as having severe consequences, since refusing an operation may have direct life-threatening consequences, unlike refusing an endoscopy.

The vignette was read aloud followed by some questions. The questions reflect the following standards: evidencing a choice, understanding, reasoning, and appreciation of the situation (box III). During reading and the interview, the participant could read the vignette as well. Answers to the questions were scored as follows: 0 points for no answer or a wrong answer, 1 point for a more or less satisfying answer and 2 points for a satisfying answer (for more details, see box III).

Cognitive performance

General cognitively functioning was measured by the Mini-Mental Scale Examination (MMSE) (Folstein *et al.*, 1975). Dementia was diagnosed according to DSM-IV criteria (DSM-IV, 1994). Despite the limitations, the MMSE is a widely used screening tool to determine

the level of cognitive functioning in patients with dementia and is often used with this purpose in studies on decision-making capacity (Fitten *et al.*, 1990; Janofsky *et al.*, 1992; Sachs *et al.*, 1994; Marson *et al.,* 1995b; Fazel *et al.,* 1999; Kim *et al.,* 2001, 2002). However, it was stressed that the MMSE is not a valid instrument to assess decision-making capacity (Fitten *et al.*, 1990; Janofsky *et al.*, 1992; Rutman & Silberfeld, 1992; Etchells *et al.*, 1999; Feinberg & Whitlach, 2001). An advantage of the MMSE is that it provides insight in the actual cognitive functioning. This is important, as it is well known that decision-making capacity may fluctuate in time due to fluctuations in the severity of the disease, like dementia (Appelbaum & Grisso, 1988).

The MMSE consists of 20 items and scores range from 0-30, higher scores indicating better cognitive functioning. The sum score consists of the following elements: orientation in time and place, memory, attention, language and visual construction. Patients with scale scores < 16 were regarded as severely demented patients who would not be able to participate in the interviews. Included were patients with a score ≥ 16, of which patients with scale score of 16-23 were considered as cognitively impaired (Tombaugh & MacIntyre, 1992; Etchells *et al.,* 1997).

Demographics and control variables

The demographic variables age, gender education, marital status, and domestic situation were assessed, to evaluate possible differences between the two randomly selected groups. Education was assessed by a question about the highest educational level completed. These data were converted into total years of education. Marital status was defined as single, married, divorced or widow, dichotomised in married and not (or no longer) married. The domestic situation was distinguished in living totally independently and (semi-) dependently.

Data analysis

Baseline characteristics were compared for subjects from both groups. Differences between the two groups were tested with the *t* test for independent samples and the χ 2 test as appropriate.

Differences in decision-making capacity between the two vignettes were evaluated by *t* test for independent samples for the ability to evidence a choice, to understand, to reason, and to appreciate a situation. These tests were performed for both groups in total as well as for cognitively impaired and non-impaired subjects in each group. All differences were tested two-sided.

Associations between cognitive functioning and decision-making capacity were controlled for demographic characteristics with (co) variance analyses (ANCOVA).

Results

Two groups of elderly patients, each including patients with MMSE scores ranging from 16-30, were compared with respect to two treatment situations characterized by different levels of severity in consequences. In table 1 the characteristics of the sample are given. No significant differences between the two groups were found for mean age, gender, education, marital status, living situation, diagnosis dementia, and cognition. Overall, the highest percentage of participants was female, widow, low educated, and lived independently.

Differences in demographic characteristics were tested between cognitively impaired and non-impaired patients in both groups (table 2). In the group confronted with the vignette with mild consequences a significant difference between cognitively impaired and non impaired patients was only found for domestic situation. Patients with cognitive

Table 1: Sample characteristics

	Vignet A n (%) / M (sd)		Vignet B n (%) / M (sd)		P-values
Gender					
- Male	21	(37.5)	22	(44.9)	
- Female	35	(62.5)	27	(55.1)	0.442
Age	81.3	(6.5)	81.1	(6.9)	0.832
Years of education	8.26	(3.0)	8.98	(3.5)	0.281
Marital Status					
- Married	21	(37.5%)	19	(38.8%)	
- Not married	35	(62.5)	30	(61.2)	0.893
Domestic situation					
- Independent	43	(76.8%)	35	(71.4%)	
- (Semi-)dependent	13	(23.2%)	14	(28.6%)	0.531
Diagnosis dementia					
- no dementia	40	(71.4%)	32	(71.4%)	
- cognitively impaired or dementia	16	(28.6%)	12	(24.5%)	0.886
Missing	1	(1.8%)	5	(10.2%)	
MMSE 16-30	24.5	(3.5)	23.8	(4.0)	0.414

Table 2: Differences in demographical characteristics, diagnosis dementia and cognitive functioning (MMSE) of cognitively impaired and non impaired subjects in vignettes with mild or severe consequences.

	Mild consequences Endoscopy anaemia e.c.i					Severe consequences Operation colon cancer				
	MMSE≤23 (n = 19)		MMSE>23 (n=37)		*P*-values*	MMSE≤23 (n = 21)		MMSE>23 (n = 28)		*P*-values*
	M	(sd)	M	(sd)		M	(sd)	M	(sd)	
Gender:										
- Male	7	(36.8%)	14	(37.8%)		5	(23.8%)	17	(60.7%)	
- Female	12	(63.1%)	23	(62.2%)	0.781	16	(76.2%)	11	(39.3%)	0.010
Age	81.0	(7.0)	81.5	(6.3)	0.781	82.3	(6.1)	80.1	(7.5)	0.289
Years of education	8.0	(3.1)	8.4	(3.0)	0.667	8.8	(3.6)	9.1	(3.6)	0.769
Marital status:										
- married	6	(31.6%)	15	(40.5%)		8	(38.1%)	11	(39.3%)	
- not married	13	(68.4%)	22	(59.5%)	0.512	13	(61.9%)	17	(60.7%)	0.933
Domestic situation:										
- independent	11	(57.9%)	32	(86.5%)		16	(76.2%)	19	(67.9%)	
- (semi-)dependent	8	(42.1%)	5	(13.5%)	0.016	5	(23.8%)	9	(32.1%)	0.523
Diagnosis dementia:										
- no dementia	6	(31.6%)	34	(91.9%)		7	(33.3%)	25	(89.3%)	
- dementia	13	(68.4%)	3	(8.1%)		12	(57.1%)	0		
Missing	0		1	(2.7%)	0.000	2	(10.5%)	3	(10.7%)	0.000
MMSE (16-30)	20.2	(2.1)	26.6	(1.6)	0.000	19.8	(2.2)	26.9	(1.9)	0.000

*t-test for two independent samples, level of significance p<0.05

Table 3: Mean scores of decision-making capacity in the vignettes with mild or severe consequences.

	Mild consequences Endoscopy anaemia e.c.i (n = 56)		Severe consequences Operation colon cancer (n = 49)		*P*-values*
	M	(sd)	M	(sd)	
Evidencing a choice (0-2)	1.85	(0.41)	1.86	(0.46)	.976
Understanding (0-6)	4.16	(1.70)	4.80	(1.38)	.038
Reasoning (0-8)	3.36	(1.19)	3.43	(0.91)	.758
Appreciation (0-4)	3.15	(1.06)	3.29	(0.98)	.487
Total score (0-20)	12.38	(3.48)	13.37	(2.88)	.118

* t-test for two independent samples, level of significance p<0.05

impairment lived relatively more semi-dependently than non-impaired patients. In the group confronted with the vignette with severe consequences a significant difference between cognitively impaired and non-impaired patients was only found for gender. Cognitively impaired patients consisted relatively of more women than non-impaired patients. No significant differences were found in demographic characteristics, diagnosis dementia, and cognitive functioning between the groups (vignette A and B) for either cognitively impaired or non-impaired patients.

Table 4: Mean scores of decision-making capacity of cognitively impaired and cognitively non-impaired subjects in vignettes with mild or severe consequences.

	Mild consequences Endoscopy anaemia e.c.i					Severe consequences Operation colon cancer				
	MMSE≤23 (n = 19)		MMSE>23 (n = 37)		*P*-values*	MMSE≤23 (n = 21)		MMSE>23 (n = 28)		*P*-values*
	M	(sd)	M	(sd)		M	(sd)	M	(sd)	
Evidencing a choice (0-2)	1.72	(0.58)	1.92	(0.28)	.183	1.90	(0.30)	1.82	(0.55)	.533
Understanding (0-6)	3.37	(1.77)	4.57	(1.54)	.011	4.10	(1.67)	5.32	(0.82)	.001
Reasoning (0-8)	2.67	(1.61)	3.70	(0.74)	.017	3.48	(0.93)	3.39	(0.92)	.755
Appreciation (0-4)	2.56	(1.20)	3.43	(0.87)	.003	3.24	(1.37)	3.32	(0.86)	.772
Total score (0-20)	9.95	(3.92)	13.62	(2.48)	.000	12.71	(3.44)	13.86	(2.32)	.171

* t-test for two independent samples, level of significance p<0.05

In table 3 the mean scores are shown of the vignette with mild or severe consequences. It can be concluded that the situation with severe consequences was better understood than the situation with mild consequences. No significant differences were found for evidencing a choice, reasoning, appreciation, and total scores between both groups.

The association between severity of consequences, decision-making capacity, and cognitive functioning is shown in table 4. Within the group of the vignette with mild consequences significant differences between cognitively impaired and non-impaired were found for understanding, reasoning, appreciation, and the total vignette score. Cognitively impaired participants performed worse on these abilities than cognitively non-impaired participants. Domestic situation did not influence the association between decision-making capacity and cognitive functioning. Within the group confronted with the vignette with severe consequences cognitively impaired participants only performed significantly worse on understanding. Gender was not found to influence the association between decision-making capacity and cognitive functioning.

Comparing the two treatment situations for each subgroup of either cognitively impaired or non-impaired, it was found that subjects without cognitive impairment only showed a significant difference on understanding (mean vignette A: 4.57 vs. mean vignette B: 5.32, $p = 0.022$). No significant differences between the two treatment situations were found for evidencing a choice, reasoning, appreciation, and the total vignette score. However, within the group of subjects with cognitive impairment a significant difference was found for the total vignette score (mean vignette A: 9.95, mean vignette B: 12.71, $p = 0.023$). While not significant, there was some indication that the situation with severe consequences scored better on both reasoning (mean vignette A: 2.67 vs. mean vignette B: 3.48, $p = 0.071$) and appreciation (mean vignette A: 2.56 vs. mean vignette B: 3.24, $p = 0.076$).

Discussion

This study evaluates the influence of different contexts and consequences on assessing decision-making capacity in a population of elderly subjects with (and without) cognitive impairment. Decision-making capacity was assessed with clinical vignettes in two comparable groups. It was found that the performance in the treatment situation with severe consequences was better than in the situation with mild consequences. This effect was especially found in elderly with cognitive impairment. These findings contrast with our initial presumption that a treatment situation with severe consequences would require more of patients' abilities with regard to decision-making than a situation with mild consequences.

How can these findings be explained? We assumed that the random selection constituted two comparable groups, which was confirmed for demographic characteristics and degree of cognitive impairment. Furthermore, the methodology to assess decision-making capacity was equal in both groups. Explanations of the differences must thus be found in the specific content of the vignettes differing in their complexity and severity of consequences.

With regard to this complexity it can be concluded that, in contrast to earlier statements, situations with more severe consequences should not necessarily be considered as more complex choices (Fitten *et al.*, 1990). Our study shows that the situation with severe consequences was significantly better understood than the situation with mild consequences. This finding is in agreement with the theoretical consideration of Beauchamp and Childress, who argue that many non-risky situations require more ability than many risky situations (Beauchamp & Childress, 1994).

With regard to the influence of cognition, significant differences between impaired and non-impaired in all standards were found, especially in the situation with mild consequences.

This finding is consistent with earlier studies on the relationship between decision-making capacity and cognitively impaired elderly (Marson *et al.*, 1995a, 1995b; Schmand *et al.*, 1999). In case of severe consequences, only understanding was negatively influenced by cognitive impairment. The group of subjects with cognitive impairment understood the situation with severe consequences better than the situation with mild consequences. This suggests that the situation with mild consequences may be considered as more complex, in terms of requiring more of the individuals' abilities associated with decision-making capacity.

When the severity of consequences does not determine the complexity of a situation, what makes a decision more complex than another decision? Theories of decision-making have mentioned heuristic tools like representativeness and availability of information to explain people's decision-making (Kahneman, *et al.*, 1982). People intuitively evaluate choices by the degree in which a situation resembles other known situations, or by the ease with which known situations come to mind (situations people are familiar with). In other words: choices not resembling known situations, like for instance an endoscopy, may be experienced as more complex than choices resembling known situations. In this study elderly patients are probably more familiar with knowledge about cancer and operations, than with the specific methods of a stomach investigation. This might explain that the situation with mild consequences was more difficult to understand than the situation with severe consequences.

Another explanation for the differences in the assessment of decision-making capacity can be found in the severity of consequences of the vignettes. Our findings can perhaps be connected to the discussion on emotion and competence (Charland 1998, 1999). Damasio has argued that emotions are essential to practical reasoning and decision-making (Damasio, 1994, 2000). Nowadays a central idea in cognitive emotional theory is that emotion involves appraisal. Appraisal is regarded as a process whereby one interprets and evaluates the significance of events and situations in the environment in light of learned or pre-set goals and expectations (Lazarus & Lazarus, 1994). The particular context of a choice with life-threatening consequences may in general provoke more feelings of personal relevance than a choice with less severe consequences. The choice of whether or not to undergo an operation for colon cancer may provoke more feelings of personal relevance than a choice to undergo an endoscopy with mild consequences.

Although this study raises some interesting questions about decision-making capacity and a decision's complexity and its consequences, there are some limitations to be mentioned as well. First, the effects of a particular treatment situation on one's decision-making capacity are clearer when two situations are tested in one person. In this study we only tested one situation in one participant to avoid burden. To compare two situations we had to rely on the comparability of the two groups. Demographic characteristics were comparable for the two groups, as well as in the subgroups of cognitively impaired and non-impaired subjects. When demographic characteristics could not be compared, the effect of the variable on the association cognition and decision-making capacity was tested. However, no significant effects were found. Secondly, the MMSE was used to assess the degree of cognitive functioning. An important limitation of the MMSE is the educational bias. However, variance analyses did not show significant influence of education on the association between cognitive functioning and decision-making capacity (results not shown). Thirdly, although decision-making capacity in psycho-geriatrics has earlier been assessed with the vignette method (Stanley *et al.*, 1984, 1988; Fitten *et al.*, 1990; Sachs *et al.*, 1990; Marson *et al.*, 1995b; Fazel *et al.*, 1999; Schmand *et al.*, 1999), questions can nevertheless be asked about the validity and reliability of the method. It was argued that face-validity is demonstrated by the element of a particular treatment situation (Fitten *et al.*, 1990;

Appelbaum & Grisso, 1995). Face-validity can also be demonstrated in the standards used to assess competence. Standards used in the vignettes are based on legal standards, which have been discussed for decades (Roth *et al.*, 1977; Appelbaum & Roth, 1982; Appelbaum & Grisso, 1988). With regard to reliability: several studies, including our own, have reported satisfying inter-rater reliability (Marson *et al.,* 1995a, Grisso *et al.*, 1997; Fazel *et al.,* 1999; Carpenter *et al.,* 2000).

Our findings have consequences for another element of validity, namely the hypothetical character of the vignettes. The question of decision-making capacity always comes up in real treatment situations. What do reactions towards a hypothetical choice predict about the actual situation and its consequences as experienced by patients? How can we safeguard comparability of the complexity and consequences of the hypothetical situation to the actual situation of the patient? Especially when the comparability is not only determined by medical technical arguments, but is largely determined by a patient's personal value system. Until now only one study evaluated the effect of information about hypothetical and realistic situations on the process of understanding (Grisso & Appelbaum, 1991). It was suggested that patients understood information easier when it was related to their disease, as compared to general information not related to their personal situation. It seems therefore advisable to perform future research on assessing decision-making capacity in real life decisions to account for personal experiences of choice situations. Experiences in assessing decision-making capacity in actual situations obtained within the context of psychiatry may serve as a guide in these studies (Grisso *et al.*, 1997; Kitamura *et al.*, 1998; Appelbaum *et al.*, 1999).

Further discussion is also needed about the sliding scale concept of competence. It has been argued that the criteria of competence should be more stringent in situations with severe consequences than in situations with mild consequences (Drane, 1985; Buchanan & Brock, 1989). Our findings suggest that people may react differently towards situations with a different degree of severity in consequences. Apparently, people are for a longer period of cognitive impairment able to make their judgement in a situation with severe consequences. It seems therefore doubtful that a causal association exists between the severity of consequences as we judge it and the requirements experienced by an individual. This association is part and parcel of the sliding scale concept in applying a normative judgement of competence on a psychological concept of decision-making capacity. The requirements experienced by the individual may depend heavily on earlier experiences and personal history. Further evaluation of this problem needs a qualitative analysis of people's choices, their reasons and their connection with personal values and history. Finally, a serious discussion is needed about the meaning of competence as decision-making capacity and our normative judgements based on our ideas on autonomy and beneficence.

Decision-making Capacity of Elderly Patients Assessed with the Vignette Method: Imagination or Reality?

Vellinga, A., Smit, J.H., van Leeuwen, E., van Tilburg, W., & Jonker, C. (2005). Aging and Mental Health, 9: 40-48.

Decision-making capacity of elderly patients with the vignette method: imagination or reality?

This article evaluates whether providing hypothetical or realistic information influences decision-making capacity in elderly patients with (and without) cognitive impairment. Decision-making capacity was assessed with a clinical vignette, representing the choice of whether or not to undergo an endoscopy. The following standards of decision-making capacity were evaluated quantitatively and qualitatively: the ability to evidence a choice, to understand, to reason, and to appreciate a situation. The vignette was presented to patients either in a hypothetical situation or in a real situation. In the hypothetical situation cognitively impaired patients performed significantly worse than cognitively non-impaired patients on all abilities associated with decision-making capacity (with the exception of evidencing a choice). The realistic situation showed the same pattern for the ability to understand and the total vignette score. However, cognitively impaired and non-impaired patients reasoned about and appreciated the realistic situation equally well. The qualitative analysis revealed that patients gave comparable answers in the hypothetical and realistic situation. Patients answered indifferently of the standards of decision-making capacity. Also personal circumstances were taken as reference point to make a decision, regardless of the situation. Major differences between the hypothetical and realistic situation were not found. However, our findings do raise questions about the validity of hypothetical vignettes, especially for the use in cognitively impaired persons.

Introduction

During the last decades many instruments to assess competence have been proposed in matters of consent to treatment or to participate in research (Stanley *et al.*, 1984; Stanley *et al.*, 1988; Fitten *et al.*, 1990; Janofsky *et al.*, 1992; Martin & Glancy, 1994; Sachs *et al.*, 1994; Marson *et al.*, 1995b; Grisso *et al.*, 1997; Kitamura *et al.*, 1998; Etchells *et al.*, 1999; Schmand *et al.*, 1999; Dymek *et al.*, 2001; Kim *et al.*, 2001). These instruments have in common that competence is operationalized as decision-making capacity. They also share the importance given to information disclosure and use the same standards to assess decision-making capacity: the ability to evidence a choice, to understand, to reason, and to appreciate a situation. One major difference comes up when various instruments are compared. Within psychiatry decision-making capacity is determined in realistic treatment situations, whereas in psycho-geriatrics decision-making capacity is mainly evaluated in hypothetical research situations with vignette methods (Vellinga *et al.,* 2004).

It was argued that the hypothetical vignette method could approximate the 'real-life' physician assessment situation (Marson *et al.*, 1995b). However, a hypothetical situation is different from a real-life situation, which may influence the assessment of decision-making capacity. Performances may either be heightened by greater motivation to reach a good decision about a personally relevant issue or be reduced by anxiety that attends the consideration of one's own situation (Appelbaum & Grisso, 1995).

Until now the effects of hypothetical or realistic methods on the assessment of decision-making capacity has not been thoroughly investigated. Only one study considered the effect of hypothetical or realistic information disclosure on the ability to understand (Grisso & Appelbaum, 1991). Patients were found to understand information related to their psychiatric illness better than hypothetical information about a somatic illness. This finding suggests that providing hypothetical or realistic information may lead to different results in assessing the ability to understand. It was not evaluated whether other decisional abilities, like evidencing a choice, reasoning, and appreciation, are influenced as well by information disclosure in either a hypothetical or realistic way.

Within psycho-geriatrics (hypothetical) vignettes have mainly been used to assess decision-making capacity. Elderly persons with cognitive impairment demonstrated a significant worse performance than cognitively non-impaired control subjects with regard to the understanding of treatment and research situations, to the manipulating of information rationally, and to the appreciation of the situation (Stanley *et al.*, 1988; Fitten *et al.*, 1990; Marson *et al.*, 1995b; Fazel *et al.*, 1999; Schmand *et al.*, 1999; Dymek *et al.*, 2001; Kim *et al.*, 2001).

The focus of this study is to evaluate the effect of providing either realistic or hypothetical treatment information on the assessment of decision-making capacity in elderly patients, comparing cognitively impaired with non-impaired persons. First, the degree of decision-making capacity will be quantitatively compared in two similar groups of elderly patients. Secondly, the content analysis will be performed of the categories of understanding, evidencing a choice, reasoning and appreciation will be qualitatively described. In this way we will be able to describe the individual´s level of performance (quantitative scores), and may possibly explain that performance by the qualitative analysis (Marson *et al.*, 1999).

Methods

Study sample

The sample was selected among patients, aged 65+, visiting a geriatric ward for a somatic and psychiatric screening and patients visiting a gastro-enterology ward. Inclusion was based on newly-admitted patients.

Excluded were patients who were not able to participate in the interview, like blind patients, patients who were not native speakers and patients with moderate and severe dementia (Mini-Mental State Examination < 16). These patients were not able to participate in the interview, as it consisted of questionnaires which partly required reading in the Dutch language and which are only valid in patients with a MMSE above 16. Patients who obtained the treatment described in the vignette within one year before the moment of our interview were excluded as well. Their performance may be influenced by their actual experience.

In total 245 patients were approached to participate. Of this population 34 (14%) refused to participate, 35 (14%) indicated they were too ill or exhausted, and 24 (10%) could not be interviewed due to logistical problems. Ten patients (4%) had a MMSE score lower than 16, and did not reach the inclusion criteria. Eventually, 142 patients were included, which equals a participation rate of 60%.

The remaining 142 patients were divided in three groups. The first group consisted of 37 patients who were actually proposed to undergo an endoscopy. Decision-making capacity was assessed with a vignette disclosing information about their actual situation. The remaining 105 patients were randomly divided in two groups. They were confronted with a hypothetical treatment vignette about either an endoscopy or an operation for colon cancer (Vellinga *et al.*, 2002). In this study the group of patients confronted with the realistic vignette (n = 37) will be compared with the group of patients confronted with the hypothetical vignette, representing the choice of whether or not to undergo an endoscopy (n = 56). Approval for this study was given by the local medical ethics committee. Informed consent was obtained of all respondents.

Interviewers

A researcher (physician, first author), research nurses, and psychologists performed the interviews. They were thoroughly trained for performing the interviews in this study. The training consisted of an introduction of the questionnaire by the first author, a test interview performed by the interviewer on the first author and an interview of a participant, performed in attendance of the first author. Extra attention was given to the recognition of possible confusion caused by questions about a hypothetical situation in cognitively impaired patients. Interviews were audio taped in order to monitor the quality of the data-collection. Feedback on the interviews was given to the interviewer during the total period the data-collection.

Decision-making capacity: the vignette method

Decision-making capacity was assessed with a clinical vignette, describing the choice of undergoing an endoscopy for anaemia (box I). The structure of the vignette is in line with vignettes described in earlier studies (Sachs *et al.*, 1994; Marson *et al.*, 1995b; Schmand *et al.*, 1999). The content of the vignette was developed in collaboration with experienced geriatricians and psychiatrists. The vignette was presented either in a hypothetical way during the interview, or presented after the physician had proposed the choice in reality. The vignette was not part of the clinical care of the patients. This means that the patient´s consent for the endoscopy had to be assessed by the physician, who was blind for the results of the vignette.

The vignette was read aloud, followed by some questions. The questions represented the following abilities: factual understanding, evidencing a choice, reasoning and appreciation of the situation (Grisso *et al.*, 1997). During the reading and the interview, the participant was allowed to read the vignette. Answers to the questions were scored as follows: 0 points for no answer or a wrong answer, 1 point for a more or less satisfying answer (this is an answer partially containing elements of the vignette or elements of personal arguments, which are not given in the text. For example: 'I don't want to undergo an investigation', because of my high age) and 2 points for a satisfying answer (box III). The inter-rater reliability (Cohen's Kappa) of the vignettes is 0.64, which represents 78% agreement between the raters.[10] The content of choice, consent or refusal, was administered in all interviews. All interviews were audio taped. The audiotapes were converted into transcripts in order to perform a descriptive analysis.

Cognitive performance

Dementia was diagnosed according DSM-IV criteria (DSM-IV, 1994). Cognitive function was measured by the Mini-Mental State Examination (MMSE) (Folstein *et al.*, 1975). Despite the limitations, the MMSE is a widely used screening tool for establishing the level of cognitive functioning in patients with dementia and is often used with this purpose in studies on decision-making capacity (Fitten *et al.*, 1990; Janofsky *et al.*, 1992; Sachs *et al.*, 1994; Marson *et al.*, 1995b; Fazel *et al.*, 1999; Kim *et al.*, 2001; Kim *et al.*, 2002). However, it was often stressed that the MMSE is not a valid instrument to assess decision-making capacity (Fitten *et al.*, 1990; Janofsky *et al.*, 1992; Rutman & Silberfeld, 1992; Etchells *et al.*, 1999; Feinberg & Whitlach, 2001). An advantage of the MMSE is that it provides insight in the actual cognitive functioning. This is important, as it is well known that decision-making capacity may fluctuate in time due to fluctuations in the severity of the disease, like dementia (Appelbaum & Grisso, 1988).

Patients with scale-scores lower than 16 were regarded as moderately or severely demented patients who would not be able to participate in the interview. Included were patients with scale-scores greater than or equal to 16. Patients with scale-scores between 16 to 23 were considered as cognitively impaired (Tombaugh & MacIntyre, 1992). An argument in favour for this cut off is based on the finding that people with a SMMSE scale score 16 to 23 have an increased risk of impairment in decision-making capacity, whereas people with a score of 24 to 30 can serve as a 'normal' control group (Etchells *et al.*, 1997).

Demographics

The demographic variables age, gender education, marital status, and domestic situation were included in the analyses to assess possible differences between the two selected groups. Education was assessed by a question about the highest educational level completed. These data were converted into total years of education. Marital status was dichotomised in married and not married. Domestic situation was converted into living totally independent and living (semi-) dependent. Living (semi-) dependent includes patients who live in nursing homes as well as senior homes.

Data analysis

Baseline characteristics were compared for subjects from both groups. Differences in the continuous variables age, education, and MMSE were tested two-sided with the *t* test for independent samples. Differences in gender, marital status, domestic situation, and diagnosis dementia were evaluated with the χ 2 test.

[10] To examine inter-rater reliability, vignettes of 45 participants were rated by both a research assistant and one of the authors (AV). Kappa was computed for the total vignette score, which was divided into tertiles.

Differences in decision-making capacity between the hypothetical or realistic situation were evaluated by the *t* test for independent samples (two-sided). These tests were performed for the total sample as well as for cognitively impaired and non-impaired subjects in each group. For all statistical test $p < 0.05$ is adopted as level of significance.

Twenty randomly selected transcripts from both the hypothetical and realistic situation were qualitatively compared. The analysis consisted of two parts: a content analysis and a frequency score of subjects selected by the content analysis in both the realistic and hypothetical situation. The content analysis was performed by distinguishing topics out of the patients´ answers with respect to the questions about understanding, evidencing a choice, reasoning and appreciating a situation.

Results

Two groups of elderly patients, with and without cognitive impairment, were compared with respect to hypothetical or realistic vignettes containing a treatment proposal. Table 1 shows most of the participants are female, single, and live independently. No significant differences were found for gender, age, education, marital status, domestic situation, diagnosis dementia and cognitive functioning between the groups confronted with either the realistic or the hypothetical vignette. Except for domestic situation no significant differences were found between cognitively impaired and non-impaired subjects (results not shown). In the group confronted with the hypothetical vignette a significantly higher percentage of participants with cognitive impairment lived (semi-) dependently (Pearson Chi-square: 5.757, P = 0.016). No significant differences between the hypothetical and realistic situation were found for cognitively impaired persons (results not shown).

Table 1: Sample characteristics

	Hypothetical (n=56) n (%) / M(sd)		Realistic (n=37) n (%) / M(sd)		*P*-values
Gender					
- Male	21	(38%)	11	(30%)	0.440
- Female	35	(63%)	26	(70%)	
Age (y)	81.3	(6.47)	82.0	(7.63)	0.681
Education (y)	8.3	(3.03)	8.0	(2.53)	0.668
Missing	3		1		
Marital Status					
- Married	21	(38%)	8	(22%)	0.106
- Not married	35	(63%)	29	(78%)	
Domestic situation					
- Independent	43	(77%)	25	(68%)	0.326
- (Semi-)dependent	13	(23%)	12	(32%)	
Diagnosis dementia					
- no dementia	40	(71%)	21	(57%)	0.889
- dementia	16	(29%)	9	(24%)	
Missing	0		7	(19%)	
MMSE (y) 16-30	24.5	(3.54)	23.3	(3.74)	0.147

Table 2 shows the mean scores of decision-making capacity in the hypothetical and realistic treatment situations. No significant differences were found between the two situations. With exception for reasoning, the scores on the different abilities tended to be somewhat higher in the realistic situation.

Table 2: Mean scores of decision-making capacity in the realistic and hypothetical situation.

	Hypothetical (n=56) M	(sd)	Realistic (n=37) M	(sd)	*P*-values*
Evidencing a choice (0-2)	1.85	(0.41)	1.97	(0.16)	0.055
Understanding (0-6)	4.16	(1.70)	4.54	(1.41)	0.263
Reasoning (0-8)	3.36	(1.19)	3.35	(0.95)	0.958
Appreciation (0-4)	3.15	(1.06)	3.38	(0.76)	0.223
Total score (0-20)	12.38	(3.48)	13.24	(2.23)	0.146

*t-test for two independent samples, level of significance $p < 0.05$

Table 3 shows the effect of hypothetical or realistic information disclosure on the assessment of decision-making capacity in cognitively impaired and non-impaired patients. Cognitively impaired patients performed significantly worse in the hypothetical situation with respect to the ability to understand, to reason, and to appreciate the situation. Also their total vignette score was significantly lower in comparison to cognitively non-impaired patients. In the realistic situation significant differences between cognitively impaired and

Table 3: Mean scores of decision-making capacity of cognitive impaired and cognitive non-impaired subjects in the hypothetical and realistic situation.

	Hypothetical MMSE≤23 (n = 19) M	(sd)	MMSE>23 (n=37) M	(sd)	*P*-values*	Realistic MMSE≤23 (n = 16) M	(sd)	MMSE>23 (n = 21) M	(sd)	*P*-values*
Evidencing a choice (0-2)	1.72	(0.58)	1.92	(0.28)	0.183	1.94	(0.25)	2.00	(0)	0.333
Understanding (0-6)	3.37	(1.77)	4.57	(1.54)	0.011	3.94	(1.29)	5.00	(1.34)	0.021
Reasoning (0-8)	2.67	(1.61)	3.70	(0.74)	0.017	3.13	(0.72)	3.52	(1.08)	0.210
Appreciation (0-4)	2.56	(1.20)	3.43	(0.88)	0.003	3.31	(0.87)	3.43	(0.68)	0.651
Total score (0-20)	9.95	(3.92)	13.62	(2.48)	0.000	12.31	(1.99)	13.95	(2.18)	0.024

*t-test for two independent samples, level of significance $p<0.05$

non-impaired patients were found for the ability to understand and the mean total vignette score. No significant differences were found for the abilities to reason and to appreciate the situation. Cognitively impaired patients appreciated the realistic situation better than the hypothetical situation (respectively 3.31 and 2.56, p=0.042) and obtained a significantly higher mean total score (respectively 12.31 and 9.95, p=0.036).

The content of decision: a qualitative approach

After content analysis of the transcripts of both the hypothetical situation and the realistic situation two general remarks can be made. First, analysis of the answers in the different categories (understanding, choice, reasoning, and appreciation) was difficult, because patients answered the questions indifferent of the categories. For example, when questions about understanding the proposed treatment were posed, patients immediately answered by giving their treatment preference and accompanying reasons. Questions reflecting different abilities of decision-making are rather artificial in comparison to the way decisions are actually made. An example to clarify this remark:

I: Can you tell something about the proposed treatment? (hypothetical)[11]
R (61): That examination, of course I want to undergo it. I would like to know the cause of my complaints.
I: But can you tell something about that examination?
R (61): It is a tube to watch the stomach. Of course I´ll do it. I would like to know what is the matter.

Second, patients referred to their own circumstances in both the hypothetical and realistic situation. They mentioned for instance their actual complaints instead of the described hypothetical complaints, or described personal experiences or experiences of friends or family to underline their arguments:

I: Can you mention advantages and disadvantages of the proposed treatment? (hypothetical)
R (76): (advantage: appropriate treatment can be given). A disadvantage is that everything remains untreated. And the anaemia will stay longer. All these circumstances and treatment. I can´t handle it no longer. I´m getting tired only to think about it. I have had little, how can you call it, I have had little too much lately. Something like, don´t bother, I don´t see the meaning of it anymore…I´m getting tired of everything. If I would have been 20 years younger, I would have consented immediately.

I: Can you tell something about the disease? (hypothetical)
R (25): That I know the cause, an ulcer of the stomach. I know that it causes pain. My husband had two ulcers of the stomach. He died because of them.

Answers reflecting personal experiences were especially found in the category of understanding. In the hypothetical situation the interviewer often had to emphasize that the respondent should imagine to be in the situation as described, after which the respondent correctly answered the question in the second instance. In the hypothetical

[11] *(in italics)* are remarks of the author.

situation many subjects mentioned the possibility that the complaints may be caused by cancer, instead of describing the illness or complaints as given in the vignette (anaemia or faecal blood loss). With regard to the proposed procedure, in both situations patients described the procedure. However, patients in the hypothetical situation tended to mention more often their own situation and reasons whether or not they want to undergo the procedure. The advantages of undergoing this examination of the stomach were similar in both situations (table 4). Advantages mostly mentioned were to increase the knowledge about one's health situation and the possibility of curing the underlying disease. Disadvantages mostly mentioned were a painful or distressing examination procedure (table 4). In the hypothetical situation some patients mentioned that not undergoing the examination may have negative consequences for one´s health. In the realistic situation some patients expressed the disadvantage of the possibility of being confronted with a malignant disease (which can be judged as a correct disadvantage, but is not described in the vignette). With respect to evidencing a choice one important aspect regards that some patients stressed they actually don't feel have a choice. They experienced their situation as beyond their control (regardless of a hypothetical or realistic situation):

I: Can you express whether or not you want to be treated? (realistic)
R (147): Yes, I´ll have to. I´ll have to do this examination. Yes, I do not have another choice.

This feeling was also expressed by the subject of ´necessity´ as an important reason to undergo the examination and which was also mentioned as an appreciation of the situation. An analysis of the choice content of all patients (n = 93) revealed that an equal amount of patients refused the proposed examination (hypothetical situation: 23% refusals, realistic situation 24% refusals, Chi square: 0.034, p=0.853).

Reasons to consent to an endoscopy were the security of knowledge about the medical cause and the expectation that the underlying disease may be treated (table 4). In comparison of the hypothetical and realistic situation a difference appeared with regard to the subject of experienced complaints. In the realistic situation the experienced complaints were a reason to undergo the proposed examination, and the absence of complaints was mentioned as reason for not undergoing the examination as well. However, the subject of complaints was not mentioned as reason to consent or refuse further examination by patients in the hypothetical situation.

With regard to appreciation (table 4), both the hypothetical and the realistic group appreciated the situation as fearful or stressful. However, patients in both groups also acknowledged that an examination may eventually improve their health. In the realistic situation patients seemed to be more uncertain: they expressed more often the attitude of 'wait and see' and were less secure about the influence of the examination on their health and the opinion of the family than patients in the hypothetical situation. In both situations patients expected that the opinion of the family will be in concordance with their decision and it was also emphasized that the family will have the opinion that the choice is up to the patient herself.

Discussion

In comparing two groups of elderly patients in a vignette study on an optional treatment with an endoscopy for anaemia, no significant quantitative differences were found between the hypothetical and realistic situation. In this study the findings of Grisso et al. (1991) could therefore not be replicated. However, although they found significant group-by-form

Table 4: Qualitative analysis of decision-making capacity: numbers of answers of 40 patients given in both the hypothetical (H) and realistic (R) situation.

Understanding	**H**	**R**
Advantages:		
No advantages	1	1
Illness can be cured	12	9
Security about cause	10	12
Don't know	1	1
Avoid cancer to spread	1	1
Bad news is argument not to live	2	0
Reduce stress	0	2
Disadvantages:		
No disadvantages	2	3
Pain or discomfort	12	9
Fear	1	2
Knowing malignant cause	0	2
Wait and see	1	2
No examination: bad for health	5	2
Don't know	1	3

Reasoning	**H**	**R**
Consent:		
Security about cause	5	4
Necessity	0	2
Illness can be cured	6	5
Doctor knows best	0	3
Cannot live with complaints	0	5
Refusal:		
High age	3	0
Too ill	1	1
No complaints	0	3
Nasty examination	0	2
Avoid cancer to spread	2	0
Responsible for children	1	0
Life meaningless	1	0

Appreciation	**H**	**R**
Appreciation of the situation:		
Fear/bad	4	7
Obligation to be cured	0	1
Relief (not undergoing)	0	1
Necessity	2	3
May be malignant	0	2
Improving health	4	5
Worsen health	2	0
Wait and see	2	4
Don't know	3	0
End of life is near	2	0
Influence on health:		
Positive influence	11	5
Negative influence	2	1
Wait and see	2	3
Nothing	1	3
Don´t know	1	5
Attitude of family:		
´Decide yourself´	6	6
Will agree	9	5
Will disagree	0	1
Feelings family	7	5
Does not affect family	0	2
Don´t know their opinion	2	5

interactions, the group means only showed a small tendency for mentally ill patients to perform somewhat better on the form representing their actual psychiatric illness than on the forms representing a hypothetical somatic illness (Grisso & Appelbaum, 1991). This last finding is confirmed by our study outcomes.

Our finding could indicate that hypothetical vignettes can be used equally well as realistic treatment situations to assess decision-making capacity. This is underlined by our qualitative analysis, which shows that regardless of the test situation participants give comparable answers. With respect to understanding, the description of advantages and disadvantages is comparable. Reasons mentioned in both groups are to gain knowledge about the medical cause and the possibility of treating the underlying disease. Both groups appreciate the situation as fearful and stressful. In this respect hypothetical vignettes seem to approximate real life decisions rather well (Marson *et al.*, 1995b). Further, in both the hypothetical and the realistic situation patients express the feeling of not having a choice. This finding also deserves more attention in future discussions on the concept of informed consent.

However, because decision-making capacity is especially affected in elderly persons with cognitive impairment (Fitten *et al.*, 1990; Marson *et al.*, 1995b; Schmand *et al.*, 1999), we expected to find more differences between the hypothetical and realistic situation in comparing cognitively impaired persons with non-impaired elderly patients. Although severely impaired patients were excluded in our study, significant quantitative differences regarding understanding and the total vignette score were found in both the hypothetical and realistic situation between cognitively impaired and non-impaired patients. In contrast to the hypothetical situation, no significant differences were found for the ability to reason and to appreciate the situation in the realistic situation. Cognitively impaired elderly also performed better on appreciation in the realistic situation as compared to the hypothetical situation and attained a significant higher total vignette score. This finding compromises somewhat the validity of competency assessments by using vignettes with hypothetical situations. It seems that especially patients with cognitive impairment profit from an evaluation of decision-making capacity in a realistic situation.

The qualitative evaluation of the answers revealed an important argument in favour of assessments in actual situations as well. Regardless of the test situation, participants took their own situation as starting point to reflect about the proposed treatment. Although this behaviour was labelled before as an error (Marson *et al.*, 1999), namely 'loss of detachment', we believe the error is not so much in the behaviour of the participants, but in the method of the assessment. This point of view is strengthened by the theoretical considerations of the concept of competence, especially in the situation specific character of competence. This view holds that one may be competent for a decision, and at the same moment be incompetent for another (President's Commission, 1982). Both the complexity of the decision and its consequences may influence the assessment of decision-making capacity (Lowe *et al.*, 2000; Kim *et al.*, 2001; Vellinga *et al.*, 2002).

Further, some differences appeared in the arguments patients give in either the realistic or hypothetical situation. With respect to reasons to undergo an investigation, patients in the real situation mention their complaints. This seems a rather straightforward finding, though may be of importance in assessing decision-making capacity of a demented patient. To consider reasons hypothetically may be much more complex, than experiencing the actual complaints. Another important difference is found in the appreciation of the situation. Patients in the realistic situation tend more to a wait and see attitude. This is probably, as well as the former finding, a reflection of daily medical practice: mostly decisions or not

black or white at one specific moment. Mostly alternatives may be found, or time may play an important role as well.

With regard to the standards of decision-making capacity, our qualitative results indicate that people do not make decisions as hierarchical as the model of competence suggests. This was also being confirmed by our quantitative findings: although the ability to understand is affected by cognitive impairment, no differences are found between cognitively impaired and non impaired patients for the ability to reason and to appreciate. Apparently, reasoning and appreciation do not require a profound understanding of the specific situation. The content analysis reveals that topics mentioned in these both categories are rather general, which is in line with earlier findings (Stanley *et al.*, 1988).

An important strength of our study is the combination of quantitative and qualitative analysis with regard to decision-making capacity. Especially the qualitative analysis can give insights, which remain unknown by a quantitative approach (Marson *et al.*, 1999). An other strength is that the quantitative analysis could be based on two different situations with an equal content and an equal amount of standardization, as the same vignette was used both in a realistic and hypothetical situation.

Our study also has some limitations. First, the effect of a situation on decision-making capacity could have been shown more reliably when all participants would have been confronted with both an actual and a hypothetical situation. However, besides an ethical argument to avoid burden, also logistical problems accompany this procedure. Second, the participants who received the actual information disclosure could – ethically – only be interviewed after they had spoken to the physician about the treatment proposal. In contrast to the hypothetical group, they received the information twice. However, as our interview immediately followed after the conversation with the physician, it is unlikely that a patient could have more thoroughly deliberated about the proposed treatment than patients in the hypothetical situation. Besides, a possible learning effect would have affected understanding probably more than reasoning and appreciation, as the information given twice was especially about the procedure of the examination.

What is the main conclusion? The aim was to evaluate the effect of two different situations on measuring decision-making capacity of elderly patients. It has been stressed that a hypothetical vignette simulated the realistic situation fairly well to assess decision-making capacity (Marson *et al.*, 1995b). Our findings indicate that a hypothetical situation may not resemble an actual situation well enough for the assessment of decision-making capacity. The quantitative analysis revealed that the ability to reason and the ability to appreciate the situation were only affected by cognitive impairment in the hypothetical situation. Our point of view is strengthened by the finding of the quantitative analysis that people take their actual situation as starting point of their treatment considerations. Therefore, we encourage realistic treatment situations, instead of hypothetical vignettes, to assess decision-making capacity in elderly patients.

Competence to Consent to Treatment of Geriatric Patients: Judgements of Physicians, Family Members and the Vignette Method

Vellinga, A., Smit, J. H., van Leeuwen, E., van Tilburg, W., & Jonker, C. (2004). International Journal of Geriatric Psychiatry, 19, 645-654.

Competence to consent to treatment of geriatric patients: judgements of physicians, family members and the vignette method

In absence of a gold standard of methods to assess competence, three judgements of competency of geriatric patients are evaluated: the judgements of a physician, the judgement of a family member, and the judgement of an instrument. Competence of 80 geriatric patients was judged both by a physician and a family member. Decision-making capacity was assessed with a vignette. A vignette describes a treatment choice, after which the following abilities are evaluated: evidencing a choice, understanding, reasoning and appreciating a situation. Cognitive functioning was measured with the Mini-Mental State Examination. Most of the geriatric patients were judged competent by all three methods. Disagreement between the three judgements was found for 25 patients. Agreement about incompetence was only reached for one patient. Physicians appeared to be most lenient in their incompetency judgements: only three patients were judged incompetent. These patients scored significantly lower than competent patients on cognitive functioning, the decisional ability of understanding, and the total vignette score. Family members appeared to be most stringent in their judgements: they considered 22 patients incompetent. Incompetent patients scored significantly lower than competent patients on cognitive functioning, reasoning and the total vignette score. The disagreement between the judgements suggests a difference in factors given emphasis by the three methods. The finding that both the judgements of physicians and family members are associated with the assessment of the vignette, suggests that the vignette method has more than a legal theoretical base and is associated with daily life experience and knowledge as well. Physicians can be helped to assess competence by the vignette method to evaluate decisional abilities and by family members who can provide more information about patients´ values.

Introduction

The need for an instrument to assess competence[12] to consent to treatment will presumably increase by the growing number of elderly persons with a high prevalence of both (chronic) illnesses and cognitive decline. Within the legal context competence has clear definitions. In the Netherlands competence is defined as the ability to make a reasonable appreciation of a treatment decision. Still, within clinical practice the search for a single test of competency or gold standard is comparable with the search for a Holy Grail (Roth *et al*., 1977). In clinical practice three potential judges can be assumed to give valid and reliable judgements about patients´ competency to consent to treatment: the physician, an instrument, and/or a family member. All three judgements have their strengths and weaknesses.

First, physicians are directly confronted with competency in everyday practice. They often (implicitly) assess patients´ decision-making capacity. They judge with their clinical experience and can weigh their impression of decision-making capacity along with other clinical and contextual information of patients (Grisso *et al*., 1997). Although sometimes (expert) physicians are regarded as provisional `gold standard´ (Janofsky *et al*., 1992; Fazel *et al*., 1999; Kim *et al*., 2001), studies have shown that different (expert) physicians give different judgements about the same patients, questioning their ability to give reliable judgements (Marson, 1994; Marson *et al*., 1997; Kitamura and Kitamura, 2000)

Second, many instruments have been developed to assess decision-making capacity (Stanley *et al*., 1988; Fitten *et al*., 1990; Sachs *et al*., 1994; Marson *et al*., 1995b; Grisso *et al*., 1997; Kitamura *et al*., 1998; Schmand *et al*., 1999). By the use of clearly described standards, instruments help to make a more objective judgement about decisional abilities of the patient. Most of the instruments evaluate the following four standards with a legal origin: the ability to evidence a choice, the ability to understand relevant information, the ability to reason about the choice, and the ability to appreciate the situation (Meisel *et al*., 1977). Although the use of clear standards raises the reliability of judgements, instruments can not take into account contextual information of the specific choice. Instruments using the four standards, for instance, leave aside emotions and personal values, factors that presumably play sometimes a significant role in competency as well.

Third, the family is rarely mentioned as a possible actor in the competency judgement. Two important arguments can be given to evaluate the competency judgements of family members. First, the family´s impression of a patient´s competency may be expected to be based on a shared history. With this knowledge family members can test whether the patient´s arguments are in concordance with the life the patient (has) live(d) (Appelbaum & Grisso, 1988; Kuczewski, 1996). Second, consulting of family members, who are supposed to be ignorant of the theoretical legal discussion, could shift the frame of reference from a legal orientation to one based on common knowledge (Berlin & Canaan, 1991). Emotion or personal values may be better represented in the family judgement than those of physicians or instruments. Although it has been argued that family members should have a more

[12] The terms competency and decision-making capacity should be distinguished from each other. Recently, a tendency is visible that competence is reserved for the legal context, whereas decision-making capacity refers to the judgements made by physicians in daily clinical practice. It can also be argued that decision-making capacity is a (psychological) conceptualisation of the broader (legal and ethical) concept of competence. In this article the term competence will be used to describe the dichotomous judgements of physician, family member, and vignette. The term decision-making capacity will be used to describe the scale assessment of the vignette.

central role in medical decision-making (Lindemann Nelson, 1992; Blustein, 1993; Kuczewski, 1996), the entwining of interests of family and patients is often described as well, which may lead to invalid judgements of competency.

The focus of this article is to evaluate three judgements of competency of geriatric patients: the judgements of a physician, the judgement of a family member, and the judgement of an instrument. Competence of geriatric patients is evaluated, as these patients are at risk both for complex medical decision-making and cognitive decline, which may impair decision-making capacity. A vignette method is used to assess decision-making capacity. The main hypothesis is that when a vignette is supposed to have value in clinical practice, a relation should exist between the assessment of decision-making capacity by the vignette and competency judgements of both physician and family members. To unravel this relation three judgements will be compared in terms of the frequencies of incompetent and competent judgements and the degree of agreement between them. The judgements of physician and family will also be compared with respect to decision-making capacity scores of the vignette and patient characteristics associated with diminished decision-making capacity to explain expected differences in the judgements.

Methods

Study sample

The patient sample was selected among patients, aged 65+, visiting geriatric wards for a one day somatic and psychiatric screening (July 1999 to December 2000). Inclusion was based on newly-admitted patients. Excluded were patients who were not able to participate in the interview, like blind patients, patients who were no (Dutch) native speakers and patients with severe dementia. In total 245 patients were approached to participate. Of this population 34 (14%) refused to participate, 35 (14%) indicated they were too ill or exhausted and 24 (10%) could not be interviewed due to logistical problems. Eventually, 152 patients were included.

Physicians gave their judgement about the patient's competence after they discussed the results of the clinical investigations and the possibilities of treatment with the patient. Eventually, 124 judgements were collected of 35 different physicians; 28 judgements were missing due to logistical problems. Family members or acquaintances who accompanied the patient to the hospital were interviewed before the physicians discussed the possibilities of treatment with the patient. In total 96 judgements of family members were collected; 56 patients came alone to the ward. This study evaluates patients (n=80) of whom three judgements were available.

Informed consent was obtained of all respondents: patients and family members. Approval for this study was given by the local medical ethics committee.

Decision-making capacity: the vignette method

Decision-making capacity was assessed with a clinical vignette. A vignette describes a hypothetical treatment choice, after which questions are posed to evaluate decision-making capacity. The abilities are based on standards: factual understanding, evidencing a choice, reasoning and appreciation of the situation. During the reading and the interview, the participant was allowed to read the vignette. Answers to the questions were scored as follows: 0 points for no answer or a wrong answer, 1 point for a more or less satisfying answer and 2 points for a satisfying answer (box III). The structure of the vignettes is in line with earlier described vignettes (Sachs *et al*., 1994; Schmand *et al*., 1999). The subject and content of the vignettes were developed in collaboration with experienced geriatricians and psychiatrists. Important criterions in subject choice were the fact that the medical condition and treatment procedure should have a considerable incidence and the fact that the proposal should constitute a significant choice, with a relevant risk/benefit comparison. For instance a blood examination is probably not experienced as a significant choice, as most people will estimate the benefits much higher than the risks. The vignettes described either the choice of undergoing an endoscopy for anaemia with unknown cause or the choice to undergo an operation for coloncarcinoma (see also box I and II). The vignettes were presented either in a hypothetical way during the interview (n = 61), or presented after the physician had proposed the choice in reality (n = 19). The inter-rater reliability (Cohen's Kappa) of the vignettes is 0.64, which represents 78% agreement between the raters.

Physicians' and family members' judgements

The physicians and family members gave a dichotomous judgement about competence: competent or incompetent. Physicians were not given instructions for the assessment of competence, in order to approach the judgements in daily practice as much as possible. Family members were explained that nowadays patients have the right to make their own judgements in medical decisions. One of the conditions is that patients are able to make these decisions. The ability of making medical decisions may be influenced by for example a deteriorating health state (somatic or cognitive). Subsequently, family members were asked whether they thought the patient could make a medical decision or not. The type of relation between family members and patients and the frequency of contact were registered, as well as the following demographic characteristics: gender, age, and total years of education.

Cognition, depression, physical functioning, and patient demographics

Cognitive functioning was assessed both by a clinical diagnosis of dementia and by the Mini-Mental State Examination (Folstein *et al*., 1975). Despite its limitations, the MMSE is a widely used screening tool for establishing the level of cognitive functioning in elderly patients and is often used with this purpose in studies on decision-making capacity (Fitten *et al*., 1990; Janofsky *et al*., 1992; Rutman & Silberfeld, 1992; Sachs *et al*., 1994; Marson *et al*., 1995b; Etchells *et al*., 1999; Fazel *et al*., 1999; Feinberg & Whitlach, 2001; Kim *et al*., 2001; Kim *et al*., 2002). The MMSE consists of 20 items and scores range from 0-30, higher scores indicating better cognitive functioning. The sum-score consists of the following elements: orientation in time and place, memory, attention, language and visual construction.

Depression was registered by the Geriatric Depression Scale (Brink *et al*., 1982). The GDS has an yes-no format to exclude possible bias due to cognitive or concentration problems with which elderly may cope. The GDS consists of 30 items, higher scores indicating a higher degree of depression. The GDS has relatively few somatic items, which diminishes bias of somatic complaints without a relation with depression in elderly persons.

Physical functioning was operationalized in three different ways. First, the number of chronic diseases was registered. These were dichotomised in no or one disease and two or more diseases. Second, activities of daily living were registered with the Barthel index, with a scale score of 0-20. Higher scores indicate a higher level of functioning in daily activities, like eating or dressing (Mahoney & Barthel, 1965). Third, the instrumental activities of daily life were registered by the Fillenbaum index, with a scale score of 0-14. Higher scores indicate a lower level of functioning in instrumental daily activities, like making a phone call or shopping (Fillenbaum, 1985).

The demographic variables age, gender, education, marital status, and domestic situation

were registered. Education was assessed by a question about the highest educational level completed and converted into total years of education (range 5-18 years). Marital status was defined as single, married, divorced or widow, dichotomised in married or not married. The domestic situation was distinguished in living totally independently, living (semi)-dependently.

Data analysis

Frequencies were computed for the judgements of physician, family member and vignette method. The vignette score was dichotomised by using a 95% criterion cut off score of the population of patients without cognitive impairment or dementia (Schmand *et al*., 1999). Degree of agreement was computed by kappa. T-tests and chi-square tests were performed to evaluate differences in cognitive functioning, depression, physical functioning, decision-making abilities, and demographic characteristics between patients who were judged either competent or incompetent by physician, family or vignette.

Results

Sample

Table 1: Demographic characteristics of patients

	Patients (n = 80) Freq. (%) / M (SD)	
Age (years)	82.60	(6.26)
Gender		
- Males	34	(42.5%)
- Females	46	(57.5%)
Education (years)	8.66	(3.28)
Marital status		
- married	32	(40%)
- not married	48	(60%)
Living situation		
- independent	62	(77.5%)
- (semi) dependent	18	(22.5%)
Cognition		
Dementia:		
- yes	30	(37.5%)
- no	47	(58.8%)
- missing	3	(3.8%)
MMSE (0-30)	22.94 (n=79)	(4.69)
Depression		
GDS (0-30)	10.71	(6.34)

Table 1 shows demographic characteristics of the patients, their mean cognitive functioning, and mean degree of depression. Most of the patients were female, not married and lived independently. Almost one third of them had a diagnosis of dementia. Table 2 shows demographic characteristics of the family members and provides information about their relation with the patients. Most of the family members were female, they were most often a spouse or child of the patients, and mostly had a daily or weekly contact.

Table 2: Demographic characteristics of family members

	Family members (n = 80) Freq. (%) / M (SD)	
Age (years)	60.33	(12.59)
Gender		
- Male	26	(32.5%)
- Female	54	(67.5%)
Education (years)	11.14	(3.21)
Type of relation		
- spouse	16	(20.0%)
- child	49	(61.3%)
- other (family second or third degree, family in law or acquaintance)	15	(18.9%)
Frequency of contact		
- daily	41	(51.3%)
- weekly	28	(35.1%)
- monthly	11	(13.8%)

Frequencies of incompetence, judged by physician, family member or vignette method

Table 3 shows the frequencies of patients judged either as competent or incompetent by their physician, their family member or the vignette method. Physicians judged most of the patients as competent, only 3 patients were judged incompetent. The family judged more stringent: 22 patients were incompetent according to their opinion. The total score of the vignette method considered 12 patients incompetent. Appreciation was the most stringent standard: judging 19 patients incompetent.

Table 3: Frequencies of incompetent and competent judgements of physician, family member and the vignette method.

	Total population (n = 80) Competent N (%)		Incompetent N (%)	
Physician	77	(96%)	3	(4%)
Family member	58	(72%)	22	(28%)
Vignette:				
- Understanding	65	(81%)	15	(19%)
- Reasoning	63	(79%)	17	(21%)
- Appreciation	61	(76%)	19	(24%)
- Total score	68	(85%)	12	(15%)

Agreement between the three judgements

Table 4 shows the agreement between physicians, family members and the vignette judgements. Total agreement between the three judgements exists for 1 incompetent patient and for 54 competent patients. In 25 patients one of the judgements about competence differs from two other judgements. Degree of agreement was also computed by kappa. Agreement between physician and family: 0.101 ($p = 0.121$); between physician and vignette: 0.220 ($p = 0.011$); and between family member and vignette: 0.343 ($p = 0.001$).

Table 4: Agreement of the judgements made by physician, family and vignette.

		Vignette: incompetent	Vignette: competent
Physician: incompetent	Family: incompetent	1	1
	competent	1	0
Physician: competent	Family: incompetent	7	13
	competent	3	54

Differences in cognition, depression, and decisional abilities between incompetent and competent patients

No differences were found in demographic characteristics between competent and incompetent patients for both physician and family members judgements. Table 5 shows differences in cognition, depression, and decision-making capacity between competent and incompetent patients. The three patients judged incompetent by the physician scored significantly lower on cognitive functioning and were less depressed than the competent patients. Two of the three incompetent patients had a diagnosis of dementia (in contrast to 28 of the 74 competent patients). The three incompetent patients all had no or one chronic disease (of the competent patients 30 had two or more chronic diseases). No significant differences between competent and incompetent patients were found for ADL or IADL. Although for the most part not significant, incompetent patients had lower scores for decisional capacities than competent patients.

Patients judged incompetent by their family members had a significant lower score on cognitive functioning, and had a significant higher proportion of patients with dementia or cognitive impairment than competent patients (12 of 20 incompetent patients had a diagnosis of dementia, opposed to 18 of 57 competent patients, Pearson chi square: 5.03 (df 1), p=0.025). No significant differences between competent and incompetent patients were found for depression. No significant difference in number of chronic diseases were found between competent and incompetent patients (5 of the incompetent patients had two or more chronic diseases, 25 of the competent patients had two or more chronic diseases, Pearson chi square: 2.83 (df 1), p=0.093). In contrast to ADL, a significant difference was found in IADL between competent and incompetent patients. Incompetent patients had a higher mean score on IADL, indicating that those patients had a lower degree of instrumental daily functioning. Incompetent patients scored significantly lower on the decisional abilities understanding, reasoning and the total score than competent patients. Although not significant, this tendency was also seen for evidencing a choice and appreciation.

Discussion

This article evaluates the competency judgements of physicians, family members and the vignette method in a population of geriatric patients, part of which had cognitive impairment or dementia. In order to gain knowledge about reliable and valid judgements of competency, we focused on the relation of the three judgements and the predictive value of the standards for the judgement of the physician and the judgement of the family. In general, it can be concluded that most geriatric patients, especially those with impaired cognitive functioning, were judged as competent in medical decision-making, regardless of the method of judgement (physician, family member or vignette).

First, in line with earlier findings, physicians gave more lenient judgements than family members or the vignette method (Kim *et al.*, 2001). Despite their knowledge about the

Table 5: Differences in cognition, depression, physical functioning and decision-making capacity between competent and incompetent patients, as judged by physicians and family members.

	Physician judgement Competent (n=77) M	(SD)	Physician judgement Incompetent (n=3) M	(SD)	Student´s t test for independent samples: p-values	Family judgement Competent (n=58) M	(SD)	Family judgement Incompetent (n=22) M	(SD)	Student´s t test for independent samples: p-values
Cognition (MMSE) (0-30)	23.17 (n=76)	(4.59)	17.67	(5.03)	0.05	24.07 (n=57)	(3.72)	20.00	(5.70)	0.00
Depression (GDS) (0-30)	10.94	(6.35)	5.00	(1.00)	0.00	10.50	(6.46)	11.27	(6.10)	0.63
Physical functioning:										
ADL (Barthel) (0-20)	16.12 (n=69)	(4.76)	17.67	(3.22)	0.56	16.50 (n=52)	(4.76)	15.35 (n=20)	(4.56)	0.36
IADL (Fillenbaum) (0-14)	6.95 (n=73)	(4.50)	6.33	(5.86)	0.82	6.16 (n=56)	(4.47)	9.05 (n=20)	(4.02)	0.01
Decision-making capacity (vignette)										
Understanding (0-6)	4.44	(1.60)	1.00	(1.00)	0.00	4.57	(1.56)	3.64	(1.94)	0.05
Choice (0-2)	1.84 (n=76)	(0.46)	1.67	(0.58)	0.53	1.88	(0.42)	1.71 (n=21)	(0.56)	0.23
Reasoning (0-8)	3.13 (n=76)	(1.16)	2.33	(2.08)	0.26	3.31	(1.01)	2.52 (n=21)	(1.47)	0.03
Appreciation (0-4)	3.20 (n=76)	(1.01)	3.00 (n=2)	(0.00)	0.78	3.34	(0.85)	2.75 (n=20)	(1.25)	0.06
Total score (0-20)	12.51	(3.28)	7.00	(4.36)	0.01	13.10	(2.43)	10.18	(4.74)	0.00

diagnosis dementia, physicians tended to judge patients incompetent in relatively few cases. How can this be explained? One explanation may be the idea that a person is competent unless proven otherwise. In case of incompetency a physician should have strong evidence, which may prevent them to judge this too easily. A second argument may be the problem of proportionality. Physicians should balance the harms of an incompetency judgement by the potential risk and benefits for a patient. When the risks of a treatment are relatively low, an incompetency judgement may cause more harm in terms of overruling someone, than benefit. In our study, many of the patients´ decisions concerned low risk decisions, like a change in medication or a consult at different medical specialist. Also in some cases there was no change in therapy. Because relatively few treatment proposals implied serious risks for the patients involved, physicians probably expected no harm in considering these patients as competent.

Family members judged most stringent about the competency status of patients. This finding is consistent with earlier ones. It was argued that family members, who are responsible for the care of their beloved ones, tend to a more protective attitude to avoid risks as much as possible (Biesaart & Hubben, 1997). This protective attitude is also found proxy decision-making for patients to consent to participate in research protocols (Sachs *et al*., 1994).

Second, the three judgements showed a low degree of agreement. The judgements coincide in only one incompetent patient (and 54 competent patients), while one third of the patients were incompetent according to one or two judgements. This lack of agreement can probably be subscribed to the different aspects in judgement. An important difference between the physician and family is that the physician makes a judgement based on his impression of the patient during the day of investigation, while a family member probably judges the patient´s behaviour over a long term period. The current illness and possible diminished cognitive functioning may affect the judgement of a family member more than the physician, who compares the patient´s performance with others in the same population. A difference in judgement may also be caused by the fact that family members are ignorant of the specific legal definition, while physicians may be presumed to have some knowledge of the legal definition. The vignette differs from the other two judgements in focusing on decisional abilities alone.

Third, patients who were judged as incompetent by the physicians or family mostly had a diagnosis of dementia and had a significant lower score for cognitive functioning than competent patients. Cognitive impairment can be concluded to be an important factor in being judged incompetent. No differences in degree of depression were found between competent and incompetent patients. Both findings are in line with earlier studies on the relationship between competence and cognition (Marson *et al*., 1995a; Marson *et al*., 1995b; Marson *et al*., 1999; Schmand *et al*., 1999; Kim *et al*., 2001) or depression (Appelbaum *et al*., 1999). No association was found between number of chronic diseases or ADL functioning and either the physician´s or the family member´s judgements. Interestingly, patients judged incompetent by the family members had a significantly higher mean score on IADL, indicating a worse performance in instrumental daily functioning. A possible explanation may be that a remarkable increasing dependency on activities like shopping or cooking may be extrapolated by family members to abilities like making health care decisions, resulting in a judgement of incompetency.

With regard to differences in decisional abilities between incompetent and competent patients, both physician and family members´ judgements seem to be associated with the assessment of the vignette. The findings suggest that physicians regard persons incompetent

who are relatively most vulnerable in terms of decision-making capacity, especially for the ability to understand. Although the family members judged more patients incompetent, their judgement differentiates in a reasonable way between patients with lower and higher vignette scores, especially concerning the ability to reason. This suggests that the vignette has more than a legal theoretical base and is associated with daily life experiences and knowledge as well.

Two remarks can be made with regard to the ability of family members to assess competence. The fact that they judge most stringent may rise suspicion: it may be an indication of overprotection of patients by their family members. The association between the incompetency judgement and IADL functioning may underline this statement. However, the finding that their judgement seems to be in concordance with the assessment of the vignette is reassuring. Family members seem to be able to make a reasonable estimation of their relative´s functioning. Therefore, they may reason more from their commitment to the patient than from their own interests.

Our study is limited to a relatively low number of patients of whom three judgements were available. However, the results of the analyses performed for the group of 80 patients are comparable with the results of the analyses performed for the largest groups possible (124 physician judgements and 96 family members' judgements). Therefore, it can be argued that our findings are representative for the total population of geriatric patients with and without mild to moderate dementia. A second limitation is the low frequency of incompetency judgements of the physician. The small number prevents thorough analyses of differences between competent and incompetent patients. A third limitation is that both vignette and family gave a more general judgement about competency, while physicians gave a situation specific judgement.

An important strength of this study is that the patient selection was randomly performed at a geriatric ward. Advantages of this procedure are: 1) the physicians of whom judgements are collected make these judgements regularly in daily practice and 2) the selected patients constitute a sample of the ordinary population as the physicians are confronted with on daily basis. Until now other studies have mainly focused on expert judgements of (demented) patients whose competency was already in question. In other words, this study design is developed to represent the daily problem of competency assessments at a geriatric ward.

To conclude, most of the geriatric and even mild to moderate demented patients are considered competent for medical decision-making by their physicians, families, and the vignette method. Second, there is a substantial level of disagreement between the three different judgements. Physicians are most lenient to judge someone incompetent, whereas family members have a more stringent attitude. Third, further research will have to unravel the elements of importance in judgements of physicians and family. Both the value of standards of competence, patient specific characteristics and choice specific characteristics should be evaluated. Fourth, the standards of competence seem to be based on common, everyday knowledge. This may lead to the conclusion that instruments based on these competency standards possess validity to assess competence in clinical practice.

What does this mean for the practical use of instruments to assess competence in clinical practice? To prevent that physicians will base their judgement of competence too much on contextual clinical information, instruments may provide important information about decision-making capacities and encourage the process of appropriate estimation by the treatment staff and family involved. As the family seems reasonably able to give a judgement about the patients´ competency as well, it should be taken into consideration to consult the family in competency judgements.

General Discussion

General discussion

The aim of this thesis was to identify some of the basic elements of moral capacity within the context of decision-making capacity, by means of empirical research. The first step was to examine the influence on decision-making capacity of factors that might contribute to moral capacity in elderly patients with cognitive problems. At the same time, in doing so we hoped to refine a method to assess decision-making capacity in the elderly. In the General Discussion we present a short summary of our findings, discuss methodological aspects, and the implications of our results for the concept of competence and decision-making capacity in future research, and assessment of the decision-making capacity and competence of patients with cognitive decline in daily practice.

Summary of the main findings

Knowing well or living well

We generated hypotheses (Chapter 2) in a philosophical approach to the concept of competence. The discussion about competence in Western societies is profoundly influenced by various democratic and legal theories regarding citizenship. Competent persons are considered to be citizens with the capacity to make decisions and bear responsibility. The underlying morality postulates that someone who is able to think rationally will act accordingly, and that his or her actions will thereby be what is deemed to be morally or socially good. Still, the problem of akrasia, or weakness of will, shows that mental competence does not guarantee that a person will always act in a morally responsible and rational way. On the other hand, we also argued that people who are considered to be *in*competent can still act morally responsibly. Therefore, from the moral point of view, the distinction between competence and incompetence reflects not so much a state of being, as a social norm according to which behaviour can be judged, but by relating competence to cognitive capacities, this social norm becomes a norm that focuses primarily on rational behaviour. We therefore postulated that competence and moral responsibility are overlapping human qualities, while the extent of overlap depends on the societal structure and social judgement. Within the context of mental and psychogeriatric health-care it must then be clarified how cognitive impairment can affect competence, and furthermore to what extent moral responsibility can still be maintained. This need for clarification is evident in clinical practice, where demented elderly can sometimes act as morally responsible patients, while at the same time institutional practice forces us to consider them as incompetent patients.

By considering the possibility that moral responsibility partly overlaps with cognitive competence, it becomes necessary to reconsider theories of competence in the light of the ability to act morally. Moral capacity can be defined as the capacity to make decisions based on an ongoing process to transgress the world of our personal history and beliefs into the moral standards of public institutional life. In particular, we reconsidered elements which may be connected to moral capacity. Central concepts hypothesized to be connected to the concept of moral capacity are: the role of cognition and emotion, the meaning of life, health status, personality traits and social support, and the role of the family and physician in assessing competence. To link our hypotheses with existing scientific research we chose to refine a method used to assess decision-making capacity (the vignette method). In combination with the earlier described elements possibly connected to moral capacity, we hope to develop further discussion about the issues of competence, decision-making capacity and moral capacity.

Instruments to assess decision-making capacity

Until now competence has mainly been operationalized as decision-making capacity. In comparing the various different instruments that have been developed to assess decision-making capacity in the field of medicine, the following was concluded (Chapter 5). First, the question of competence arises in a specific situation, which is reflected in the instruments by the central theme of a specific choice of treatment. The instruments have been also developed for use in specific patient populations. Secondly, the instruments presuppose that adequate medical information about the disease and treatment alternatives has been given to the patient. Thirdly, decision-making capacity is defined as the ability to evidence a choice, the ability to understand information, the ability to manipulate information rationally, and the ability to appreciate the situation. This concept of decision-making capacity has

been derived from the current legal standards. Fourthly, most studies report a high inter-rater reliability for these instruments, which means that different people using the instruments come to a comparable assessment of decision-making capacity in the same patient. Finally, two important differences appear in comparisons of the psychiatric and psychogeriatric context in which the instruments were developed. The first difference involves the realistic or hypothetical character of the information provided. The second difference involves the relationship between the scale-score for decision-making capacity and the assessment of competence. We concluded that, in spite of several limitations, most instruments to assess competence (e.g. decision-making capacity) appear to have acceptable validity and reliability, and therefore they do have added value for the assessment of decision-making capacity.

The vignette: content and character of information

The content of the vignette appeared to influence decision-making capacity in two ways. First, we compared two hypothetical vignettes which differed with regard to the severity of consequences (Chapter 6). Cognitively impaired patients scored lower than cognitively non-impaired patients on the vignette with mild consequences, whereas no difference was found between the scores of these two groups on the vignette with severe consequences. We discussed the possibility that differences in content may influence the complexity (in the meaning of the degree of severity of consequences) of the decision. In general, individuals often use heuristic tools such as representativeness and availability of information in making decisions. Moreover, the complexity of a choice not only depends on the content of the information accompanying the choice, but also on the personal experience and history of the person who has to make that choice. We hypothesized that the difference in performance with regard to decision-making capacity between different (i.e. complex and non-complex choices) hypothetical vignettes might be the result of differences in personal characteristics.

Given the context-specific character of the concept of competence, we decided to compare two vignettes, one with a hypothetical choice and one with a realistic choice (Chapter 7). A quantitative analysis showed that in the hypothetical situation cognitively impaired patients had lower scores than cognitively non-impaired patients for all decisional capacities. In the realistic situation, cognitively impaired patients had lower scores than cognitively non-impaired patients for understanding and the total vignette, but the two groups performed equally well on reasoning and appreciation. A qualitative analysis showed that patients gave comparable answers in hypothetical and realistic situations. The answers were not related to the specific standards of decision-making capacity, which may lead to questions about their presumed hierarchy in the concept of decision-making capacity. Personal circumstances were taken as a reference point for making a decision, regardless of the situation. Therefore, we questioned the validity of using hypothetical vignettes to assess decision-making capacity, and argued that the use of vignettes that refer to actual situations guarantees more validity.

Decision-making capacity and competence assessed by family and physician

Comparisons between decision-making capacity assessed by the vignette method and the judgement of competence made by the family and physicians showed a low degree of agreement (Chapter 8). The physicians were most lenient in their assessment, and the families were most stringent. The disagreement between the assessments suggests a difference in the factors emphasized by the three methods of assessment (the vignette method, judgement by family members, and judgement by physicians, respectively). Incompetence, as judged by physicians was associated with a higher degree of cognitive impairment, a lower degree of depression and a lower score for understanding, whereas incompetence judged by family members was associated with a lower degree of cognitive impairment, a lower level of IADL, and a lower score for understanding, reasoning and appreciation of the situation. The finding that the judgements made by physicians as well as the judgements made by family members were associated with standards of decision-making capacity determined by the vignette method, suggests that the vignette method has more than a legal theoretical base and is associated with practical experience and knowledge.

Methodological considerations

Sample

One limitation of our study concerns the selection of the sample from five different sources: one geriatric day clinic, two geriatric wards (long stay), one outpatient geriatric department, and one outpatient gastroenterology department. These five different sources varied in that they had either long-stay or outpatient facilities, and can therefore not be compared. This may have affected our results. For instance, patients in a hospital ward may lose their sense of autonomy, and may be less competent due to severe illness and the fact that they are hospitalized, and outpatients may have experienced more illnesses and cognitive decline than patients in a gastroenterology ward.

The possible effects of the sources could not be statistically evaluated because the number of patients in each was unequally divided, and small for most sources (most patients were selected at the day-clinic). Furthermore, the size of the effect of the source on the main results of this study is expected to be small. First, the number of patients selected in clinics other than the geriatric day-clinic was small. Secondly, the interview procedure in the other clinics was the same as the procedure in the day-clinic. Thirdly, in the analyses in which we tested the effects of the content of the vignettes on decision-making capacity, we checked for demographical characteristics, the degree of cognitive functioning, and physical health.

Another limitation in the selection of our sample concerns the absence of a group of patients who actually do face the decision of undergoing an operation for colon cancer. Comparisons can not be made between a hypothetical and a realistic situation, in which the choice has severe consequences. We were also unable to analyse the effect of the severity of the consequences on decision-making capacity in actual situations. We did not encounter such patients for several reasons. Selection was hindered by a relatively low incidence, and patients with colon cancer may follow a different route in health care. Instead of visiting a geriatric day-clinic, these patients may be treated in departments of internal medicine. Last but not least, there are ethical objections against including such patients.

An important strength of our sample selection was the random selection of patients from a geriatric ward. This procedure has two advantages with regard to selection bias, because it provides a sample of the population that physicians are confronted with on a daily basis. Therefore, selection bias due to including only 'incompetent' or patients 'at risk of being incompetent' was prevented. Furthermore, the physicians who made the assessments were physicians who make such assessments regularly in daily practice. Therefore, there was no bias due to the selection of 'expert' physicians, or physicians who might have a specific interest in the assessment of competence.

Decision-making capacity: the validity and reliability of the vignette method

The face-validity of the vignette is assessed by the degree to which the vignette represents important elements of the concept of competence, and it is satisfactory. It focuses on a specific choice of treatment, about which information is given, and it incorporates standards of competence with a substantial theoretical base (Fitten *et al.*, 1990; Chapter 5).

Expert validity of the vignette and its standards was shown in the pilot study carried out by Gouwenberg et al. (1997). They demonstrated that an expert panel of different disciplines (people with a legal background, psychologists, psychiatrists, geriatricians, general practitioners, people with an ethical background, nurses, nursing home physicians, and elderly people) regarded the vignette method as a useful instrument (74%) (Gouwenberg *et al.*, 1997).

The structure of the vignette used in this study to assess decision-making capacity is in line with earlier described vignettes (Fitten *et al.*, 1990, Schmand *et al.*, 1999). It presents a treatment choice and provides information about the illness, its treatment and the advantages and disadvantages of the treatment. The specific content of the vignette used in this study was developed in collaboration with experienced geriatricians, to reflect a relevant medical decision. The questions asked to assess decision-making capacity are based on standards of competence about which there is a sufficient degree of consensus (Chapter 5).

Based on the results of Chapters 6 and 7 we argue that the actual treatment choice should provide the context to assess decision-making capacity. Hypothetical choices for treatment in vignettes may resemble actual choices, but are not sufficiently comparable to the actual situation of the patient. A hypothetical choice may differ in complexity, which is not only determined by the complexity of the content of the choice, but also by the personal experience of the patient (Chapter 6). Furthermore, especially patients with cognitive impairment had a lower score for specific decisional capacities when the assessment was based on a hypothetical vignette. They performed better in real situations (Chapter 7). Qualitative analysis revealed that patients take their own situation as a reference point for decision-making (Chapter 7). Combining these findings with the general view that the level of competence is context-dependent, we argue that the assessment of decision-making capacity is best performed in real situations. Instruments used for the assessment should be structured to guarantee that the necessary information is provided (compare Grisso *et al.*, 1997; Kitamura *et al.*, 1998).

In contrast to the results of the pilot study (Gouwenberg *et al.,* 1997), we did not find a (reasonably) high correlation between the physician's judgement and the vignette assessment (Chapter 8). Instead, we found a low level of agreement between the vignette assessment and the judgements made by family members and physicians (Chapter 8). A possible explanation is that the physicians were not given guidelines to assess competence, and they were not informed about the patient's performance on the vignette, unlike the situation in the earlier study (Gouwenberg *et al.,* 1997).

Construct validity was demonstrated by the fact that a significant relationship was found between the vignette scores and the degree of cognitive impairment of the elderly patients. Vignette scores were significantly lower in patients with a higher degree of cognitive impairment. These findings are in line with the results of earlier studies (Gouwenberg *et al.*, 1997; Marson *et al.*, 1995a, 1995b). Also in line with an earlier study, we found that level of education was not a significant factor in the results of the vignette (Schmand *et al.*, 1999).

The assessments of evidencing a choice and understanding seem to be rather straightforward, however, reasoning and appreciation are more subject to the assessor's own normative point of reference. Discussion about the scoring of decisional capacities is necessary to reach consensus between the raters. In line with earlier studies we reached a good inter-rater reliability (Chapter 4).

In conclusion, the vignette method seems to be a valid and reliable method to assess decision-making capacity. Furthermore, our study indicates that a method reflecting the realistic situation as a starting point seems to be a more valid way to assess decision-making capacity than a hypothetical situation.

Cognitive functioning

In this thesis the MMSE was used to assess the degree of cognitive functioning. The degree of cognitive functioning was important in two ways: a cut-off score of 16 was an important inclusion criterion and the MMSE score was also used to distinguish between cognitively impaired and cognitively non-impaired persons in Chapter 6 and 7.

Despite its limitations, the MMSE is a widely used screening tool to determine the level of cognitive functioning in patients with dementia, and it is often used for this purpose in studies on decision-making capacity (Fitten *et al.*, 1990; Janofsky *et al.*, 1992; Sachs *et al.*, 1994; Marson *et al.,* 1995b; Fazel *et al.,* 1999; Kim *et al.,* 2001, 2002). However, it has also been stressed that the MMSE is not a valid instrument to assess decision-making capacity (Fitten *et al.*, 1990; Janofsky *et al.*, 1992; Rutman & Silberfeld, 1992; Etchells *et al.*, 1999; Feinberg & Whitlach, 2001). One advantage of the MMSE is that it provides insight into the actual cognitive functioning. This is important, because it is well known that decision-making capacity may fluctuate in time, due to fluctuations in the severity of the disease, such as in dementia (Appelbaum & Grisso, 1988). Patients with scale-scores from 16 to 23 were considered to be cognitively impaired (Tombaugh & MacIntyre, 1992). An argument in favour for this cut-off point is based on the finding that patients with an MMSE scale-score of 16 to 23 have an increased risk of impairment in decision-making capacity, whereas people with a score of 24 to 30 can serve as a 'normal' control group (Etchells *et al.*, 1997).

Judgements made by physicians and family members

Our analyses of the three types of judgements were based on 80 patients, instead of the total group of 146 patients, because of missing data (we collected 124 assessments made by physicians and 96 assessments made by family members). Selection bias is estimated to be low, because analyses performed for the largest possible group showed the same results with regard to the demographic data of the group of patients and the demographical data of the family members. Analysis of the relationship between decision-making capacity and judgements of competence on the one hand, and between these judgements and cognition, depression, and physical functioning, on the other hand, showed comparable results.

Ethical questions and empirical findings

This thesis describes empirical findings concerning an ethical subject. As such, this study belongs to the field of empirical ethics. Empirical ethics is based on five presumptions (Borry *et al.,* 2004): (1) research of moral attitudes, intuitions, behaviours, and reasons generates information that is meaningful for ethical theory and should be the starting point of ethical reflection; (2) empirical research based on methodology of social sciences is a proper way of describing this reality; (3) the classical distinction between normative and descriptive ethics should be more flexible; empirical ethics denies the incomparability between those two approaches and beliefs that they are fundamentally complementary; (4) empirical ethics is a heuristic term that pleads for integration of research methods and

ethical reflection; (5) empirical ethics is not anti-normative: if only context determines the values of good and wrong, you cannot use the term ethics anymore.

Our study of competence and decision-making capacity is based on comparable presumptions. By using different (quantitative and qualitative) methods we tried to promote further discussion on the ethics of competence. Using empirical data at a descriptive level, and trying to interpret these data at a more normative level, is a sensible way in which to study the subject of competence, because this concept involves both descriptive and normative levels (Berghmans, 2000).

The normative starting point in this thesis is a phenomenological view of the concept of moral capacity. However, the theory on competence has been mainly influenced by a liberal medical ethical tradition in which autonomy is one of the main values. Within this context, competence is operationalized as decision-making capacity. The method we used to assess decision-making capacity functions in between a descriptive and normative level. By describing the effect of decision-making capacity in different situations, and by comparing decision-making capacity with more normative judgements made by physicians and family members, we tried to discuss the normative starting point of the liberal medical ethical tradition. In the following section we will discuss the significance of our empirical findings for the concept of moral capacity.

Knowing well or living well

In Chapter 2 'Knowing well or living well' we argued that the fundamental question was whether or not moral responsibility and rationality are necessarily related to each other. The problem of akrasia, or weakness of will, implies that mental competence does not necessarily imply that a person acts morally. Within the context of treating demented elderly patients, we found that although cognitive impairment may affect competence, moral responsibility may still be maintained. From a phenomenological point of view one can argue that each individual is structured by social norms in a unique way. This uniqueness is a result of specific events in our life world that we have to cope with and give meaning to. In contact with social institutions we have to transgress our personal beliefs and transform them into reasons that are acceptable in public and institutional life. Our empirical results provide arguments that confirm our initial hypotheses.

Instruments developed to assess competence can be considered as representative of institutional life. As we have already argued, competence has been operationalized as decision-making capacity by these instruments (Chapter 5). A feature underlining the institutional character of the instruments is the central role of the medical information that is provided and the understanding of this information within a specific context (Chapter 5). The underlying presumption is that in order to make a morally responsible choice, patients should understand and reason about medical information, i.e. the type of illness, the possible treatment with risks and benefits, and any alternative treatments. Even in the decisional capacity of 'appreciation' – which supposes a personal element in medical decision-making –, patients are urged to transgress their personal world and to transform their personal hopes and beliefs into medically acceptable reasoning. Major criticism resulting from this phenomenological view is that the instruments used to assess competence in this way cannot fully evaluate moral capacity. Therefore, we would stress that the unique social structure and the accompanying personal narratives of individuals are an unavoidable part of their life and their competence. Trying to escape these truths would jeopardize their reality as human beings.

Another feature underlining the institutional character of such instruments lies in their legal origin. In early discussions on competence an attempt was made to formulate standards

of competence, by analysing the jurisdiction on competence. Arguments used in the judgements of competency were categorized in standards of competence (Chapter 5, compare Roth *et al.,* 1977; Appelbaum *et al.*, 1982), which represent a hierarchy of different levels of assessing competence. Depending on the risk/benefit ratio of the situation and the acceptance or refusal of the treatment, one standard is chosen to assess competence (Roth et al., 1977). With the development of assessment instruments, the standards constitute a social reality as a concept of decision-making capacity, thereby suggesting that this capacity is a personal (psychological) characteristic. By operationalizing the standards as expression of the decision making capacity, it then seems that an attempt is being made to solve a normative problem, which is a product of social institution, at a descriptive level as a personal characteristic (Berghmans, 2000). But even at a descriptive level we may question the validity of the presupposed rationality underlying the concept of decision-making capacity.

Criticism can be directed at two different levels: external and internal rationality (Charland, 2002). In the context of decision-making capacity, internal rationality refers to the hierarchical structure of cognitive abilities. The idea is that one should comprehend information, after which rational manipulation and appreciation can follow. From the results of our analysis this hierarchical structure of decision-making capacity can be questioned. Cognitively impaired patients and cognitively non-impaired patients were equally able to reason and appreciate the situation, although the cognitively impaired were less able to understand the information (Chapter 7). The qualitative analysis showed that the answers given to the questions do not represent the categories of decision-making capacities (Chapter 7).

External rationality refers to the evaluation of the content of an argument according to socially accepted norms, and is a process of 'rationalisation'. In medical institutions an individual with his/her personal history is urged to interact with this institution and its own rationality. Our analyses of the three different judgements of competence (physician, family members, and vignette method) demonstrate that different sources provide different judgements of the same individual. These different sources have different concepts of reality and probably express different expectations in their rational judgement. When judging competence, physicians are probably influenced by factors such as the type of treatment decision and the severity of its consequences for the patient: patients are held responsible as long as the consequences of their choice do not seem to be harmful from a medical point of view. Family members probably think that patients are not acting rationally in decision-making if they have impairments in other domains of their life world. In both cases the decision-making capacity functions as a concept within a broader institutional reality. We wonder if the rationality contained in that institutional reality, and henceforth in the concept of decision-making capacity, fully reflects the moral self of the patient. In the next paragraph we will discuss the relationship between decision-making capacity and moral capacity.

In assessing cognitively impaired patients with the vignette method, we found some indirect evidence that decision-making capacity and moral capacity do not completely overlap or coincide. First, the majority of demented patients were assessed as competent by physicians, family members, and the vignette method. Cognitive impairment does not lead straightforwardly to an assessment of incompetence. Secondly, we hypothesized that personal life history and emotion influence the assessment of decision-making capacity. Presenting different vignettes (differing in severity of the consequences, or the hypothetical or realistic character of the vignette) resulted into different degrees of decision-making capacity (Chapters 6 and 7). The qualitative analysis demonstrated that patients respond

primarily from their own personal point of view to the vignette (Chapter 7). Based on these findings, we conclude that moral capacity overlaps with decision-making capacity, but is not necessarily fully contained by it. Cognitively impaired elderly people may still be able to make morally responsible decisions, based on different degrees of decision-making and on their personal history. By introducing the concept of moral capacity we were able to question the validity of the concepts of competence and decision-making capacity within the context of respect for autonomy. This may result in rejecting replacement of the concept of competence by the concept of decision-making capacity, favouring in this way the enhancement of moral capacity. However, we would stress that the medical dilemmas with which the patient is confronted in clinical practice can not simply be overcome by focusing exclusively on the personal values and history of the patient and disregarding the values of medical practice. The solution is more complex, and cannot be found in the avoidance of one of the existing different realities. In our opinion, this means that physicians, as well as patients and their family members, have to deal with the combined issues of medical and individual values. We conclude with the statement that assessment instruments need to be used with caution in this interaction. They represent a starting point based on the societal reality of competence in medical practice, and should open the way to discussions about the underlying personal hopes and beliefs of the patient.

Some alternative ethical considerations

The issue of competence is mainly discussed from the point of view of the liberal medical ethics of respect for autonomy, in which competence acts as a hinge between the principles of respect for autonomy and benevolence. The issue of competence can also be considered from another ethical point of view. Criticism of the liberal medical ethical tradition falls into two categories. The first category criticizes the fact that autonomy is the main principle, and therefore proposes a different value. The second category accepts autonomy as the main value, but stresses life history and identity as important elements in decision-making. Subsequently, we will briefly discuss examples from both categories of criticism, and conclude with a short reply to both.

The first category deals with the ethics of care, a recently developed stream of ethics that challenges autonomy as the central value in medical ethics. It is argued that care itself should be the central value. The starting point of ethics of care is the interdependence of human existence, and emphasis is laid on the relational self that is connected with other relational selves. 'Care for the threat of being abandoned' has more moral meaning than 'the threat of interference by others' (Hertogh & Verkerk, 2002). Ethics of care does not disrespect autonomy, but claims that people cannot become autonomous without the support of others and their care. With regard to the care of demented people, it has been argued that the inner experience of the patient should be the starting point of ethical deliberation and action, not the objective questions concerning care (Hertogh & Verkerk, 2002). Issues of competence, according to this approach, do not presuppose that patients with dementia are free within the barriers of competence or cognitive impairment, but that patients need to be cared for in such a way that they feel that they are being approached as competent or free individuals (Hertogh & Verkerk, 2002).

Within the second category the criticism focuses on the fact that the liberal tradition defines autonomy as based on a negative meaning of freedom. Negative freedom means that people are autonomous if they can act free *from* others. Autonomy should also include a positive meaning of freedom, for instance in the sense that it gives a personal direction and meaning to a person's life. From this perspective, different approaches to the issue of competence have been proposed. First, emotions are regarded as important sources of knowledge, instead of limiting factors in (cognitive) decision-making. In other words, cognitive abilities are not the only relevant factors, but the emotional and affective reactions of a person to a particular situation are equally important. It is stressed that an unexpected emotional reaction should not be considered as incompetence, but should be the starting point of a hermeneutic interpretation (Widdershoven & Berghmans, 2002). Secondly, it is argued that personal identity and identification precede conscious decision-making, and are in fact guiding it, even though the personal identity of patients with dementia can be problematic. Agich claims, therefore, that people living in nursing homes should not be helped with making choices, but rather be supported to accept their life within a context of vulnerability, loss, and death (Agich, 1993; in Widdershoven & Berghmans, 2002). A third point of view focuses on the communicative aspects of the assessment of competence. Within this approach the emphasis lies on the process of communication that should be directed at assisting the patient to make his or her decisions, instead of on the issue of decisional authority. In the dialogue between physician and patient, attention should not only be paid to treatment-specific information, but the personal values of the patient should also be discussed. In this perspective competence is not static, but a dynamic process in physician-patient interaction (Widdershoven & Berghmans, 2002). This form of communicative ethics has recently been described by Widdershoven as therapeutic paternalism (Widdershoven, 2005).

Two comments are relevant with respect to these alternative ethical perspectives. First, the emphasis on emotion, personal values, and life history should, in our opinion, always be incorporated in clinical practice as well as in theorizing about competence and decision-making capacity. A liberal view of respect for autonomy does not deny this obligation, but stresses the respectful attitude for the patient's decision-making and moral capacity, even if the patient is cognitively impaired. Care ethics and communicative ethics, or therapeutic paternalism, do not deny the need for this respect for patients and their history, but try to classify it as secondary to the social norms of the institutional reality. Our analysis of the vignette method showed that physicians and family members are thereby most likely to reconfirm their own point of view instead of respecting the patient. Secondly, the emphasis on communication and hermeneutics almost suggests that a 'good' communication can make assessments of competence unnecessary. Although we support the idea that competence is not static but dynamic, we think that good communication cannot replace or completely solve the difficulties involved in the judgement of competence. The ideal of good communication disregards the fact that we live in social institutions that confront us with all kinds of norms. Furthermore, there will always be situations in which an ultimate assessment of competence will be necessary, and cannot be avoided in clinical practice. Even if there is good communication, the relationship between the care-giver and the patient remains in that respect a-symmetrical. Focusing on communication and hermeneutics may even cloud a transparent ethical assessment. The use of a method to assess decision-making and moral capacity and an explicit formulation of the arguments regarding the likelihood of severe consequences must be included in the discussion with the patient, the family members, and other physicians.

Societal implications

A frequently mentioned negative effect of operationalizing competence with an instrument is the possibility of 'overlegalizing' the medical daily practice. 'Overlegalisation', or 'juridification' points to the fear that good clinical practice may lose in quality by increasing attention to

formal procedures, while at the same time decreasing attention to the well-being of the individual patient. In our opinion, this does not apply to an instrument to assess decision-making capacity. Of course, every instrument needs to be interpreted as a formal action, but the aim of such a procedure is to make essential assessments in care-giving ethically transparent and accessible to others. Comprehensive ethical decisions should lead to the best possible care for every individual patient. An assessment of competence has major consequences, because it does or does not allow the patient to make his or her own decisions. In other words, it touches the core of patient autonomy, no matter what further interpretation is given to that concept. The impact of a false positive or a false negative assessment may lead to severe problems for an individual patient. Therefore, everything that can possibly improve assessments of competence should be done to provide good clinical healthcare.

Furthermore, it is well known that the diagnosis of dementia does not imply that the patient is incompetent, but it is still debatable whether incompetent or partially incompetent patients have the capacity to make morally relevant decisions about their health and future life. The findings of this study may foster the further emancipation of elderly patients with dementia. Elderly people in general, and especially patients with a chronic psychiatric illness, have to cope with ageism and prejudices. An instrument to assess decision-making capacity may increase awareness of the fact that these people may still have the ability to make (moral) decisions about their own lives.

This thesis mainly describes a method to assess decision-making capacities within the context of treatment decisions, making use of instruments similar to those that have been proposed within the context of informed consent to participate in research (Chapter 5). As the elderly are regarded as a vulnerable group, it is important to use a method that can protect those who cannot decide, and provide the opportunity to participate in research for those who are able to decide for themselves. Especially because the law prohibits scientific research on incompetent patients, unless special conditions are fulfilled, a closer investigation on the issue of informed consent is needed, and should be recommended for future research.

One final implication of this thesis concerns to the decision-making capacity of elderly people with dementia who request euthanasia. During recent years there has been much discussion in the Netherlands about the question of whether or not euthanasia requests from people with dementia can be honoured. The question of unbearable suffering in people with dementia can not be solved by our findings about decision-making and moral capacity or competence. With regard to the question of competence, our findings indicate that patients with mild to moderate dementia still have the moral capacity to make such specific requests and the comparable treatment decisions concerning palliative care. Our findings do not allow extrapolation to requests for euthanasia, because the content of such a request is different from that of normal treatment decisions. However, our findings are in favour of taking euthanasia requests from patients with dementia seriously, because many of these patients may still be competent to make such a request.

Implications for future research

From the above discussion the implications for future research can be subdivided into three categories. The first category concerns issues with regard to rational decision-making and its relationship with moral capacity, based on personal values and life history. We have posed questions with regard to the rational way in which people are supposed to make decisions, and we have argued that patients are urged to adapt to specific forms of rationality in social institutions. It has been suggested that decision-making capacity may need to be placed in a broader context, in which intuitive thinking and emotions also play a role. More specific to the medical context, patients who do not seem to know much about their illness or treatment, can still be clear about what they want. Future research should focus on the way (medical) information is used in treatment decision-making, and the way in which emotion and personal values interact with rationality. More knowledge about these aspects may affect the importance of the decisional capacities that are currently included in our vignette. Within this context the data on meaning of life, social, support and personality, which have been gathered as part of this study, should be analyzed in relation to the different judgements of competence and the concept of moral capacity.

The second category concerns issues related to the normative character of both the assessment of competence and decisional capacities. Future research should investigate the assessment of competence in daily practice, in order to unravel the current normative arguments. We need to investigate the situations in which the question of competence arises (and the situations in which the issue does not arise). Factors to specify such situations should involve not only patient characteristics, but also situational characteristics such as the severity of the diagnosis and prognosis. A qualitative analysis of the arguments concerning assessments of competence and the role of family members is equally important. Within this category it is reasonable to analyse the differences in the argumentation with regard to different illnesses (compare assessments of the competence of demented versus schizophrenic patients), different choices (compare treatment decisions with euthanasia requests) and different cultures (compare assessments of competence in different countries as well as assessments of the competence of migrants).

The third category concerns research on the effect of introducing a method to assess decision-making capacity in clinical practice. We assume that an instrument to assess decision-making capacity will improve the care given to the patient. However, research should be carried out to evaluate the use of such an instrument in daily practice in terms of positive effects for the patient and the care that is provided.

Knowledge about these three categories may hopefully promote further ethical and philosophical thinking and the reconceptualization of competence and moral capacity. Although empirical knowledge may guide ethical and philosophical thinking, theoretical analysis will also be necessary to interpret the findings.

Practical implications for the assessment of competence in daily practice

The assessment of competence in clinical practice cannot wait for the results of future discussions, because we need to know how to assess competence now. Therefore, we conclude this General Discussion with some practical guidelines (compare the MacCAT-T of Appelbaum & Grisso).

Situation-specific character of an assessment of competence:
- starting point is the actual situation of the patient
- competence is related to a particular (treatment) decision
- provide information about the illness, treatment, the pros and cons of treatment and treatment alternatives
- Remember that education may improve understanding of information

Assess decision-making capacity on the basis of:
- ability to evidence a choice
- ability to understand information
- ability to manipulate information rationally
- ability to appreciate the situation

An assessment of competence is based on:
- the degree of decision-making capacity
- the severity of the consequences of the specific treatment for the specific patient

Keep in mind:
- decisional abilities may over-emphazise cognition
- normative character of the assessment of decision-making capacity
- personal values and life history in connection with the current situation
- consultation of family members
- consultation of colleagues

Summary

Summary

The aim of this thesis was to identify some of the basic elements of moral capacity within the context of decision-making capacity of elderly patients with cognitive problems, by means of empirical research. The first step was to examine the influence on decision-making capacity of factors that might contribute to moral capacity in elderly patients with cognitive problems. At the same time, in doing so we hoped to refine a method to assess decision-making capacity and competence in the elderly.

Knowing well or living well

We generated hypotheses **(Chapter 2)** in a philosophical approach to the concept of competence. The discussion about competence in Western societies is profoundly influenced by various democratic and legal theories regarding citizenship. Competent persons are considered to be citizens with the capacity to make decisions and bear responsibility. The underlying morality postulates that someone who is able to think rationally will act accordingly, and that his or her actions will thereby be what is deemed to be morally or socially good. Still, the problem of akrasia, or weakness of will, shows that mental competence does not guarantee that a person will always act in a morally responsible and rational way. On the other hand, we also argued that people who are considered to be *in*competent can still act morally responsibly. We therefore postulated that competence and moral responsibility are overlapping human qualities, while the extent of overlap depends on the societal structure and social judgement. Within the context of mental and psycho-geriatric health-care it must then be clarified how cognitive impairment can affect competence, and furthermore to what extent moral responsibility can still be maintained. This need for clarification is evident in clinical practice, where demented elderly can sometimes act as morally responsible patients, while at the same time institutional practice forces us to consider them as incompetent patients.

By considering the possibility that moral responsibility partly overlaps with cognitive competence, it becomes necessary to reconsider theories of competence in the light of ability to act morally. Moral capacity can be defined as the capacity to make decisions based on an ongoing process to transgress the world of our personal history and beliefs into the moral standards of public institutional life. In particular, we reconsidered elements which may be connected to moral capacity. Central concepts hypothesized to be connected to the concept of moral capacity are: the role of cognition and emotion, the meaning of life, health status, personality traits and social support, and the role of the family and physician in assessing competence. To link our hypotheses with existing scientific research we chose to refine a method used to assess decision-making capacity (the vignette method).

Aim and methods

In developing philosophical thinking about competence, decision-making and moral capacity, we argued that the concept of competence mainly plays a role at the level of institutional and legal thinking. By investigating various aspects of this moral capacity in relation to decision-making capacity in medical situations, we hope to identify some of the basic elements of moral capacity **(Chapter 3)**. However, the first step is to examine the influence on decision-making capacity of factors that might contribute to moral capacity in elderly patients with cognitive problems. Because the empirical framework we sketched is too extensive to be tested in one thesis, we started modestly. We wanted to investigate the influence of different circumstances in the assessment of decision-making capacity with the vignette method. Further, we focused on the influence of cognition as the most distinctive characteristic of patients with and without cognitive decline or dementia. Finally, we focused on the relationship between the assessment with the vignette method and competence judged by family members and physicians.

We interviewed 142 elderly patients visiting a geriatric day-clinic **(Chapter 4)**. An important inclusion criterion was a MMSE score above 16. In this way patients without cognitive impairments as well as patients with mild to moderate dementia were included. Besides patients we also interviewed physicians (n=35, giving a judgement about 124 patients) and attending family members (n=96). They gave their judgement on competence

independent of knowledge about the assessment of decision-making capacity by the vignette method.

The vignette method is a method to assess decision-making capacity. A vignette describes a hypothetical treatment choice, after which questions are posed to evaluate decision-making capacity. The abilities are based on standards: factual understanding, evidencing a choice, reasoning and appreciation of the situation. The vignettes described either the choice of undergoing an endoscopy for anaemia with unknown cause or the choice to undergo an operation for colon cancer. The vignettes were presented either in a hypothetical way during the interview, or presented after the physician had proposed the choice in reality. The 142 patients were divided in three groups. The first group consisted of 37 patients who were actually proposed to undergo an endoscopy. Decision-making capacity was assessed with a vignette disclosing information about their actual situation. The remaining 105 patients were randomly divided in two groups. They were confronted with a hypothetical treatment vignette about either an endoscopy or an operation for colon cancer.

Instruments to assess decision-making capacity

Until now competence has mainly been operationalized as decision-making capacity. In comparing the various different instruments that have been developed to assess decision-making capacity in the field of medicine, the following was concluded **(Chapter 5)**. First, the question of competence arises in a specific situation, which is reflected in the instruments by the central theme of a specific choice of treatment. The instruments have been also developed for use in specific patient populations. Secondly, the instruments presuppose that adequate medical information about the disease and treatment alternatives has been given to the patient. Thirdly, decision-making capacity is defined as the ability to evidence a choice, the ability to understand information, the ability to manipulate information rationally, and the ability to appreciate the situation. This concept of decision-making capacity has been derived from the current legal standards. Fourthly, most studies report a high inter-rater reliability for these instruments, which means that different people using the instruments come to a comparable assessment of decision-making capacity in the same patient. Finally, two important differences appear in comparisons of the psychiatric and psycho-geriatric context in which the instruments were developed. The first difference involves the realistic or hypothetical character of the information provided. The second difference involves the relationship between the scale-score for decision-making capacity and the assessment of competence. We concluded that, in spite of several limitations, most instruments to assess decision-making capacity appear to have acceptable validity and reliability, and therefore they do have added value for the assessment of decision-making capacity.

The vignette: content and character of information

The content of the vignette appeared to influence decision-making capacity in two ways. First, we compared two hypothetical vignettes which differed with regard to the severity of consequences **(Chapter 6)**. Cognitively impaired patients scored lower than cognitively non-impaired patients on the vignette with mild consequences, whereas no difference was found between the scores of these two groups on the vignette with severe consequences. We discussed the possibility that differences in content may influence the complexity (in the meaning of degree of severity in consequences) of the decision. In general, individuals often use heuristic tools such as representativeness and availability of information in making decisions. Moreover, the complexity of a choice not only depends on the content of the information accompanying the choice, but also on the personal experience and history of the person who has to make that choice. We hypothesized that the difference in performance with regard to decision-making capacity between different (i.e. complex and non-complex choices) hypothetical vignettes might be the result of differences in personal characteristics.

Given the context-specific character of the concept of competence, we decided to compare two vignettes, one with a hypothetical choice and one with a realistic choice **(Chapter 7)**. A quantitative analysis showed that in the hypothetical situation cognitively impaired patients had lower scores than cognitively non-impaired patients for all decisional capacities. In the realistic situation, cognitively impaired patients had lower scores than cognitively non-impaired patients for understanding and the total vignette, but the two groups performed equally well on reasoning and appreciation. A qualitative analysis showed that patients gave comparable answers in hypothetical and realistic situations. The answers were not related to the specific standards of decision-making capacity, which may lead to questions about their presumed hierarchy in the concept of decision-making capacity. Personal circumstances were taken as a reference point for making a decision, regardless of the situation. Therefore, we questioned the validity of using hypothetical vignettes to assess decision-making capacity, and argued that the use of vignettes that refer to actual situations guarantees more validity.

Decision-making capacity and competence assessed by family and physician

Comparisons between decision-making capacity assessed by the vignette method and the judgement of competence made by the family and physicians showed a low degree of agreement **(Chapter 8)**. The physicians were most lenient in their assessment, and the families were most stringent. The disagreement between the assessments suggests a difference in the factors emphasized by the three methods of assessment (the vignette method, judgement by family members, and judgement by physicians, respectively). Incompetence, as judged by physicians was associated with a higher degree of cognitive impairment, a lower degree of depression and a lower score for understanding, whereas incompetence judged by family members was associated with a lower degree of cognitive impairment, a lower level of IADL, and a lower score for understanding, reasoning and appreciation of the situation. The finding that the judgements made by physicians as well as the judgements made by family members were associated with standards of decision-making capacity determined by the vignette method, suggests that the vignette method has more than a legal theoretical base and is associated with practical experience and knowledge.

General discussion

Based on these findings, we conclude that moral capacity overlaps with competence and decision-making capacity, but is not necessarily fully contained by it **(Chapter 9)**. Cognitively impaired elderly people may still be able to make morally responsible decisions, based on different degrees of decision-making and on their personal history. By introducing the concept of moral capacity we were able to question the validity of the concepts of competence and decision-making capacity within the context of respect for autonomy. This may result in rejecting replacement of the concept of competence by the concept of decision-making capacity, favouring in this way the enhancement of moral capacity. However, we would stress that the medical dilemmas with which the patient is confronted in clinical

practice can not simply be overcome by focusing exclusively on the personal values and history of the patient and disregarding the values of medical practice. The solution is more complex, and cannot be found in the avoidance of one of the existing different realities. In our opinion, this means that physicians, as well as patients and their family members, have to deal with the combined issues of medical and individual values. We conclude with the statement that assessment instruments need to be used with caution in this interaction. They represent a starting point based on the societal reality of competence in medical practice, and should open the way to discussions about the underlying personal hopes and beliefs of the patient. The vignette method can be used for this purpose.

Samenvatting

Samenvatting

Doel van dit op empirisch onderzoek gebaseerde proefschrift is om een aantal elementen van morele capaciteit te benoemen binnen de context van de beslisvaardigheid van oudere patiënten met cognitieve beperkingen. In eerste instantie is onderzoek gedaan naar de invloed van factoren die samenhangen met de morele capaciteit op beslisvaardigheid van deze patiënten. Daarnaast wordt getracht tot verfijning te komen van een methode om beslisvaardigheid bij ouderen te meten.

Goed weten of goed leven

Vanuit een filosofische beschouwing van het concept van wilsbekwaamheid is een aantal hypotheses ontwikkeld **(Hoofdstuk 2)**. Er werd gesteld dat de discussie over wilsbekwaamheid in Westerse maatschappijen met name is beïnvloed door verscheidene democratische en juridische theorieën over burgerschap. Wilsbekwame personen zijn dan burgers die over de vaardigheid beschikken om keuzes te maken en verantwoordelijkheid te dragen. De onderliggende moraliteit veronderstelt dat iemand die rationeel is ook als zodanig zal handelen en dat zijn of haar acties daarom ook voldoen aan het idee wat als moreel of sociaal goed wordt beschouwd. Het probleem van akrasia ofwel wilszwakte toont echter aan dat mentale (wils)bekwaamheid niet altijd betekent dat mensen voortdurend moreel verantwoordelijk of rationeel handelen. Daarnaast werd beargumenteerd dat mensen die niet bekwaam worden verondersteld, wel degelijk moreel verantwoord kunnen handelen. Daarom kon worden gesteld dat wilsbekwaamheid en morele verantwoordelijkheid overlappende grootheden zijn, waarbij de mate van overlapping wordt bepaald door sociale structuren en oordelen. Hieruit volgde de behoefte om nader te verklaren in hoeverre, binnen de context van de psycho-geriatrie, cognitieve beperkingen van invloed zijn op wilsbekwaamheid en in welke mate dit effect heeft op morele verantwoordelijkheid. Voor de dagelijkse klinische praktijk is dit een noodzaak, omdat hier de ervaring is dat patiënten met dementie moreel verantwoordelijk kunnen handelen, maar tegelijkertijd artsen door het medisch discours worden gedwongen om hen als wilsonbekwaam te kwalificeren.

In beschouwing genomen dat morele verantwoordelijkheid en wilsbekwaamheid elkaar gedeeltelijk overlappen, is het noodzakelijk om theorieën over wilsbekwaamheid te herijken in het licht van het vermogen om moreel te handelen. Morele capaciteit kan dan worden gedefinieerd als het vermogen om beslissingen te nemen die zijn gebaseerd op het voortdurende proces van transgressie tussen onze persoonlijke geschiedenis en overtuigingen enerzijds en morele standaarden van sociale institutie anderzijds. In dit proefschrift worden elementen die mogelijkerwijs met morele capaciteit verbonden zijn beschouwd. Centrale concepten die hier mogelijk mee samenhangen zijn: cognitie en emotie, zingeving, gezondheid, persoonlijkheidsfactoren en sociale steun, de rol van familie en arts in de beoordeling van wilsbekwaamheid. Om de bevindingen in het raam van bestaand onderzoek naar wilsbekwaamheid te kunnen plaatsen, is ervoor gekozen om wilsbekwaamheid te operationaliseren als beslisvaardigheid welke bepaald is met een vignet methode.

Doel en methodologie

Vanuit deze filosofische bespiegelingen is beargumenteerd dat het concept wilsbekwaamheid met name een rol speelt op het niveau van institutioneel en juridisch denken. Door morele capaciteit te onderzoeken in het licht van beslisvaardigheid, wordt getracht enkele elementen van morele capaciteit te kunnen onderscheiden **(Hoofdstuk 3)**. De eerste stap is om de invloed van verschillende factoren op beslisvaardigheid van ouderen met cognitieve beperkingen te onderzoeken. De filosofische overwegingen hebben geleid tot een dusdanig uitgebreid raamwerk, dat in dit proefschrift niet meer dan een bescheiden begin kan worden gemaakt. Het onderzoek beoogt de invloed van contextuele factoren op de bepaling van beslisvaardigheid met het vignet in kaart te brengen. Hierbij is cognitie als meest onderscheidend kenmerk gekozen. Tot slot is de relatie tussen meten van beslisvaardigheid met het vignet en het oordeel over wilsbekwaamheid van artsen en familieleden onderzocht.

In totaal zijn 142 oudere patiënten onderzocht, die allen een dagkliniek geriatrie bezochten **(Hoofdstuk 4)**. Een belangrijk inclusie criterium was een MMSE score van boven de zestien. Dit betekent dat er zowel mensen werden geïncludeerd zonder cognitieve

beperkingen, als mede mensen met milde tot matige vormen van dementie. Behalve patiënten zijn ook artsen (n=35, die in totaal over 124 patiënten oordelen gaven) en familieleden (n=96) geïnterviewd. Hen is gevraagd een oordeel te geven over de wilsbekwaamheid van de patiënt, zonder dat zij op de hoogte waren van de uitslag van de vignet methode.

De vignet methode is gebruikt om de mate van beslisvaardigheid vast te stellen. Een vignet beschrijft een hypothetische behandelkeus, waarna vragen worden gesteld om de beslisvaardigheid te bepalen. De volgende vermogens worden hierbij bepaald: het vermogen om een keus uit te drukken, het vermogen om informatie te begrijpen, het vermogen om rationeel informatie te kunnen verwerken en het vermogen om de situatie te kunnen waarderen. Er zijn twee verschillende vignetten ontworpen: één beschrijft de keus om bij onbegrepen bloedarmoede een maagonderzoek te ondergaan, de ander beschrijft de keus om bij darmkanker een operatie te ondergaan. Voorts zijn de vignetten onder verschillende omstandigheden afgenomen: deels werden de vignetten als een hypothetische situatie voorgesteld, terwijl in één groep de keus met betrekking tot het maagonderzoek de realiteit betrof. Op deze wijze ontstonden drie groepen. De eerste groep bestond uit 37 personen die de keus voor een maagonderzoek daadwerkelijk kregen voorgesteld. De overgebleven 105 patiënten kregen een vignet over een hypothetische keus. Zij werden willekeurig verdeeld over twee groepen: de ene groep beantwoordde het vignet over het maagonderzoek, de andere groep beantwoordde het vignet over het ondergaan van een operatie bij darmkanker.

Instrumenten om beslisvaardigheid vast te stellen

Tot nu is wilsbekwaamheid meestal geoperationaliseerd als beslisvaardigheid. Door het vergelijken van de verschillende instrumenten die ontwikkeld zijn om beslisvaardigheid te bepalen, werden een aantal zaken geconcludeerd **(Hoofdstuk 5)**. Ten eerste komt de vraag naar wilsbekwaamheid altijd naar voren in een specifieke (behandel)situatie. Dit wordt gereflecteerd in de instrumenten, die altijd uitgaan van een specifieke behandelkeus. De instrumenten zijn veelal ontwikkeld voor toepassing in specifieke patiëntenpopulaties. Ten tweede wordt bij het gebruik van instrumenten ervan uit gegaan dat op adequate wijze informatie is gegeven aan de patiënt over de aard van de aandoening, de mogelijke behandeling, de voor- en nadelen en eventueel de alternatieven. Ten derde wordt beslisvaardigheid meestal gedefinieerd als het vermogen om een keus te kunnen maken, het vermogen om informatie te kunnen begrijpen, het vermogen om informatie rationeel te kunnen manipuleren en het vermogen om de situatie te kunnen waarderen. Deze vermogens zijn afgeleid van standaarden die in Amerikaanse jurisprudentie worden gebruikt. Ten vierde melden de meeste onderzoeken naar deze instrumenten een hoge inter-rater betrouwbaarheid. Dit betekent wanneer verschillende mensen met behulp van het instrument oordelen, zij tot een zeer goed vergelijkbaar oordeel over beslisvaardigheid van dezelfde persoon komen. Tot slot bleken er twee belangrijke verschillen te bestaan tussen instrumenten die binnen een psychiatrische ofwel een psycho-geriatrische context zijn ontwikkeld. Het eerste verschil betreft de vraag of de behandelkeus die in het instrument wordt aangeboden realistisch of hypothetisch van karakter is. Het tweede verschil betreft de relatie tussen de schaalscore van beslisvaardigheid en het uiteindelijke oordeel over wilsbekwaamheid. De conclusie luidt dat, ondanks een aantal beperkingen, de meeste instrumenten om beslisvaardigheid en wilsbekwaamheid vast te stellen een acceptabele validiteit en betrouwbaarheid hebben. Hiermee hebben deze instrumenten een toegevoegde waarde in het beoordelen van wilsbekwaamheid.

De vignet methode: de inhoud en context

De inhoud van het vignet bleek op twee verschillende manieren de bepaling van beslisvaardigheid te beïnvloeden. Ten eerste werd de invloed van de twee verschillende hypothetische situaties vergeleken: de keus voor een maagonderzoek en de keus voor een operatie bij darmkanker **(Hoofdstuk 6)**. Er werd gesteld dat deze twee situaties van elkaar verschilden in ernst van consequenties voor de patiënt. Hier bleek dat patiënten met cognitieve beperkingen lager scoorden op beslisvaardigheid dan cognitief niet beperkte patiënten bij het vignet met milde consequenties, terwijl er geen verschillen tussen deze groepen bestonden bij het vignet met ernstiger consequenties. Dit leidde tot de opvatting dat het verschil in consequenties mogelijk de complexiteit van de keus zou kunnen beïnvloeden. Over het algemeen gebruiken individuen heuristische gereedschappen zoals de vergelijkbaarheid en beschikbaarheid van informatie om keuzes te maken. Vanuit deze overweging werd afgeleid dat de complexiteit van een keus niet alleen van de inhoud van een keus afhangt, maar ook van de persoonlijke ervaring en historie van een persoon. Hieruit werd de hypothese ontwikkeld dat het verschil in beslisvaardigheid tussen de twee verschillende vignetten veroorzaakt zou kunnen worden door verschillen in persoonlijke eigenschappen.

Vanwege het context-afhankelijke karakter van het concept van wilsbekwaamheid, werd hetzelfde vignet in twee verschillende omstandigheden vergeleken **(Hoofdstuk 7)**. Het vignet betreffende het ondergaan van een maagonderzoek werd bij een groep hypothetisch voorgesteld. Bij de andere groep kregen de patiënten dit daadwerkelijk door hun arts voorgesteld. De kwantitatieve analyse liet zien dat onder hypothetische omstandigheden – op alle beslisvaardigheden – mensen met cognitieve beperkingen lager scoorden dan mensen zonder cognitieve beperkingen. In de realistische situatie scoorden mensen met cognitieve beperkingen lager op het vermogen informatie te begrijpen, maar mensen met en zonder cognitieve beperkingen hadden vergelijkbare uitkomsten op de vaardigheden redeneren en waarderen. Een kwalitatieve analyse liet zien dat patiënten vergelijkbare antwoorden geven in hypothetische en reële omstandigheden. De antwoorden correleerden niet eenduidig met de hiërarchie van de beslisvaardigheid, waardoor deze veronderstelde hiërarchische structuur ter discussie werd gesteld. De patiënten namen, ook in de hypothetische situatie, persoonlijke omstandigheden als richtsnoer voor het maken van de beslissing. Met deze bevindingen als uitgangspunt kwam de validiteit van het gebruik van hypothetische vignetten ter discussie te staan en werd beargumenteerd dat instrumenten die uitgaan van de werkelijke situatie van de patiënt meer validiteit hebben.

Beslisvaardigheid en wilsbekwaamheid beoordeeld door artsen en familieleden

Een vergelijk tussen het oordeel van artsen c.q. familieleden over wilsbekwaamheid en de uitkomst van het vignet over beslisvaardigheid toonde een geringe overeenstemming **(Hoofdstuk 8)**. De artsen waren meestal terughoudend in hun beoordeling van wilsonbekwaamheid, terwijl familieleden het meest uitgesproken waren. Bij alle methodes bleek overigens dat, ondanks cognitieve beperkingen, de grootste groep wilsbekwaam werd beschouwd. De beperkte overeenstemming tussen de drie oordelen (de vignet methode, het artsenoordeel en het oordeel van familieleden) is mogelijk terug te voeren op de verschillende factoren die van invloed zijn op de verschillende oordelen. Wilsonbekwaamheid, zoals beoordeeld door de artsen, hangt samen met ernstiger cognitieve beperkingen, een mindere mate van depressiviteit en een lagere score op het vermogen informatie te begrijpen. Daar en tegen hangt wilsonbekwaamheid, zoals beoordeeld door familieleden, samen met een lager niveau van IADL, en een lagere score op de vermogens begrijpen,

redeneren en waarderen van de situatie. De bevinding dat zowel het artsenoordeel als het oordeel van familieleden samenhangt met vermogens die worden beoordeeld in het vignet, suggereert dat de vignet methode niet slechts een juridische theoretische basis heeft, maar ook verbonden is met praktische kennis en ervaring.

Algemene discussie

Deze bevindingen leiden tot de conclusie dat morele capaciteit deels overlap vertoont met beslisvaardigheid **(Hoofdstuk 9)**. Mensen met cognitieve beperkingen zijn nog steeds in staat om moreel verantwoorde keuzes te maken die gebaseerd zijn op verschillende niveaus van beslisvaardigheid en persoonlijke geschiedenis. Door het concept morele capaciteit te introduceren, kan de validiteit van de concepten wilsbekwaamheid en beslisvaardigheid binnen de context van respect voor autonomie ter discussie worden gesteld. Dit zou kunnen uitmonden in het verwerpen van de concepten wilsbekwaamheid en beslisvaardigheid ten faveure van het concept van morele capaciteit. Er moet echter worden benadrukt dat de dilemma's waarmee de arts en patiënt in de medische praktijk worden geconfronteerd, niet simpelweg kunnen worden overwonnen door eenzijdig te richten op persoonlijke waarden en levensgeschiedenis van de patiënt en daarbij waarden van de medische praktijk te verwaarlozen. De oplossing is complexer van aard en kan niet worden gevonden in het vermijden van één van de bovengenoemde realiteiten. De conclusie moet zijn dat zowel artsen, patiënten als familieleden leren omgaan met de gecombineerde realiteit van medische en individuele waarden. Hierbij kunnen instrumenten om beslisvaardigheid te meten, mits toegepast met de nodige zorgvuldigheid, worden ingezet. Zij vormen een uitgangspunt dat gebaseerd is op de sociale realiteit van wilsbekwaamheid in de medische praktijk en openen de weg voor discussies over de onderliggende persoonlijke verwachtingen en overtuigingen van een patiënt. De vignet methode is geschikt voor toepassing van deze benaderingswijze.

Appendix

Case Report
Competence: to Decide Well to Run Risks

This chapter was published in Dutch:
Vellinga, A., & Ederveen, A. (2004). Wilsbekwaamheid: kun je 'goed' beslissen gevaar te lopen? Tijdschrift voor Psychiatrie, 46, 395-399.

Competence: to decide well to run risks

A 35 year-old man with insulin-dependent diabetes mellitus, alcohol abuse, an amnestic syndrome and dementia after a hypoglycaemic coma, is assessed twice for his competence to consent to treatment. The assessment of capacities and the seriousness of the consequences for the patient are profoundly inter-related. We therefore stress the importance of distinguishing between decision-making capacity and the seriousness of the consequences for the patient.

Introduction

Competence is a complex concept. There has been much discussion about the definition of this concept and, maybe even more importantly, about the operationalization of the concept in daily clinical practice. Efforts to determine this operationalization are usually guided by legal or ethical argumentation. In this article we relate some theoretical aspects of the concept of competence to a case description. By confronting theory with practice, and vice versa, we hope to contribute both to the theoretical discussion and to the quality of assessments of competence in daily clinical practice.

In the following case-report we focus on two assessments of competence, followed by some theoretical considerations. Subsequently, we will discuss standards of competence and the severity of the consequences of a particular choice for the patient.

Case-report

Patient A, a 35 year-old man, is admitted to a rehabilitation centre with the consequences of a diffuse brain injury after a hypoglycaemic coma. The hypoglycaemic coma was the result of badly-regulated insulin-dependent diabetes mellitus (IDDM) and alcohol abuse. Because of disorientation and wandering behaviour the patient was (involuntary) admitted to a psychiatric ward. The following diagnosis was made: an amnestic syndrome as a result of alcohol abuse and dementia, induced by a hypoglycaemic coma.

Subsequently, the treatment is continued in the rehabilitation centre (in the legal context of an involuntary commitment). Although gradual recovery is reported, insight into the illness is totally absent. The patient does not appreciate the consequences of his current state for his present and future level of functioning. He also lacks motivation to participate in a rehabilitation programme. Several times he has refused the prescribed insulin, resulting in a clinical situation with a serious risk of coma, which is the reason why he has been admitted.

After he has proven that he can use the insulin in an appropriate way, he is allowed to go home, where he receives intensive somatic and psychiatric care. His family is in charge of his finances, and supports him in his daily activities. His independent functioning is seriously limited and his self-care is minimal.

The first assessment of competence was made because the patient acts irresponsibly with regard to his use of insulin and his diet. The psychiatrist is of the opinion that the patient seems to understand the consequences of low levels of blood glucose and the risk of a hypoglycaemic coma. The patient explicitly states that he does not want to die, but this is explained as well-considered indifference. The patient argues that he is not enjoying his life, because he does not have a job or any other areas of interest. This mental status is described as follows: level of consciousness is alert. His orientation in time is possibly affected, but his orientation with regard to place and person is not. His memory about recent life events fluctuates: he does not remember the reason why he was admitted to the rehabilitation centre, although he seems to dismiss any questions about this topic. His level of intelligence seems to be lower than the mean. His thought process is described as lacking a general view. In answering the questions his thought process seems coherent, although he is not able to retain longer lines of thought. His mood is dysphoric. The affect modulates, but in a childish manner. He expresses a passive wish to die. The following is concluded: risky behaviour of a young man with a low level of intelligence and a limited overview, who consciously runs risks. The psychiatrist considers the patient to be competent. This assessment resulted in not prolonging the legal confinement of involuntary commitment and to confront the patient with his own responsibilities.

A further deterioration of the situation raises doubts about the competence of the patient in his judgement with regard to his somatic condition. He has developed an ulcus diabeticus, induced by irregular blood glucose levels. Because he refuses to take the prescribed antibiotics, an osteomyelitis develops. The surgeon prescribes drainage and antibiotics, but the patient refuses to be admitted to a hospital. The prognosis of an untreated osteomyelitis is severe: there is a considerable risk of amputation or septic shock.

Under these circumstances, a second competence assessment is made. The patient's mental status is described as follows: the patient is defensive and coercive in contact. His ability to pay attention seems to be affected: only a simple conversation about daily events is possible. His immediate memory is affected, but there are no perceptual disorders. The thought content is not affected (no delusions). The patient's mood expresses negative thoughts, but he cannot be considered to be depressed. With regard to suicide, it is reported that the patient has a passive wish to die and that he has a striking indifference with regard to his health. The psychiatrist concludes that the patient is incompetent, because of cognitive impairment caused by a diffuse brain injury. Due to cognitive impairment, the patient has severe judgemental disorders, in particular to his somatic situation: the IDDM and the osteomyelitis. In spite of education and surveillance, the patient refuses to accept antibiotics. He can not appreciate the consequences of his attitude. The continuation of this situation may result in severe somatic, persistent injury. Based on these criteria the patient is involuntary committed to a psychiatric ward of a general hospital, where he is being treated for the osteomyelitis.

Assessments of competence in theoretical perspective

Competence is often operationalized as decision-making capacity, which refers to the following abilities: the ability to evidence a choice, the ability to understand information, the ability to manipulate information rationally, and the ability to appreciate the situation (Van de Klippe, 1990; Berghmans, 2000). Table 1 shows the relationship between decision-making capacity and the two clinical assessments.

Table 1: Relationship between decision-making capacity and the two clinical assessments

Decisional abilities	Assessment I	Assessment II
Evidencing a choice	?	Refuses antibiotics
Understanding	Understanding is not affected	?
Manipulating information rationally	Well-considered choice	?
Appreciation of the situation	Lacking a general view, indifferent to the risk of death	Cannot appreciate the consequences of his behaviour

In view of the theory of competence and decision-making capacity, it is remarkable that only the second assessment mentions the ability to evidence a choice: the patient refuses the prescribed treatment. However, this is not considered as an ability, but as an argument to start the competence assessment procedure and as one of the arguments to suggest incompetence. Both the ability to understand and the ability to manipulate information rationally are taken into consideration in the first assessment, but not in the second. In the second assessment, the patient is reported to have judgemental disorders with regard to his health. However, the exact meaning of judgemental disorders is not described, making it difficult to analyse whether these disorders concern the ability to understand, to manipulate information rationally, or to appreciate the situation. In both assessments the ability to appreciate the situation (or general overview) is described explicitly.

In both judgements decisional abilities and psychiatric symptoms and diagnoses interfere. However, from a theoretical point of view it is underlined that a psychiatric diagnosis is not sufficient to classify a person as incompetent. Underlying psychiatric syndromes may affect decisional abilities, but this does not provide sufficient evidence for incompetence (Roth *et al.*, 1977; Ministry of Justice, 1994). The situation specificity of a particular choice is emphasized in assessments of competence (Appelbaum & Grisso, 1995). In other words, the patient is supposed to understand and appreciate his particular situation. Compare also the definition of competence in the Contract of Medical treatment Act: 'a person is competent if he/she is considered to be able to judge *his/her interest at hand* reasonably' (Article 446-468 of book 7BW).

The situations in which the two judgements were made differed only in the severity of consequences for the patient. At the time of the first assessment there was a severe risk of a hypoglycaemic coma, but this was not considered as an acute threat. At the time of the second assessment there was an acute risk of amputation, and possibly a septic shock. Remarkably, in both assessments the severity of the situation forms the starting point for the competence assessment procedure, as well as being an important argument in the final judgement. In the first assessment the situation does not seem to be considered as acutely dangerous for the patient, and the patient was therefore considered to have sufficient overview and was expected to bear the responsibility for his own situation. In the second assessment, the risk of amputation or septic shock seemed to lead to the assumption that the patient lacked sufficient appreciation of the situation.

Theoretical discussions on competence also address this mixture of decisional abilities and the content of a decision and its consequences. Although a 'reasonable outcome' of a choice has been mentioned as one of the standards of competence (Roth *et al.*, 1977), the general consensus is that the outcome of choice should be separated from an assessment of decisional abilities. The idea is that the assessment of competence should incorporate a decisional process, and not the outcome of choice, to prevent rationality being limited to the opinion of the majority. Secondly, the connection between content of choice and decisional abilities is also described in the sliding scale model of competence. This model indicates that the level of competence should be more stringent when the consequences are more severe (Drane, 1985). Situations with severe consequences require adequate appreciation of the situation or the ability to manipulate information rationally, whereas in situations in which the consequences are less severe adequate ability to evidence a choice may be sufficient.

In theoretical discussions it is quite easy to separate the content of the choice and the process of decision-making (or decisional abilities). However, in clinical practice these arguments are mixed up. Possibly, the connection between content and decisional abilities is even more complex in psychiatry than in other fields of medicine subject to the legal context of the Special Admissions to Psychiatric Hospitals Act (1992), in which the criteria of danger is one of the major issues. By applying the criteria of danger, the content of the choice and its (presumed and estimated) consequences are decisive in the judgement of involuntary commitment to a psychiatric hospital, whereas competence (to run the risk of danger) is not a legal requirement.

The problem of distinguishing content of choice from decisional process can not be solved easily. Decisional abilities are assumed to represent a process of decision-making,

but they are also based on normative standards. For instance: a 'good' manipulation of the information or a 'good' appreciation of the situation depends on our own normative standards applied to the other person's situation. Nevertheless, we stress the fact that an assessment of competence has two aspects: an assessment of the patient's situation and its possible consequences, and the (decisional) abilities of the patient who is being assessed. Hopefully, by critically reviewing both aspects the assessment of competence can be improved.

References

References

Abernethy, V. (1984). Compassion, control and decisions about competency. *American Journal of Psychiatry, 141*, 53-58.

Abernethy, V. (1991). Judgements about patients incompetence: cultural and economic antecedents. In: Cutter, M. A. G. & Shelp, E. E. (eds), *Competency. A study of informal competency determinations in primary care*. Dordrecht/Boston/London: Kluwer Academic Publishers, 211-226.

Alexander, M. P. (1988). Clinical determination of mental competence. A theory and a retrospective study. *Archives of Neurology, 45,* 23-26.

Altman, D. G. (1999). *Practical statistics for medical research.* Boca Raton, London, New York, Washington D.C.: Chapman & Hall/CRC.

Appelbaum, B. C., Appelbaum, P. S., & Grisso, T. (1998). Competence to consent to voluntary psychiatric hospitalization: a test of a standard proposed by APA. *Psychiatric Services, 49,* 1193-1196.

Appelbaum, P. S. (1997). Psychiatric research and the incompetent subject. *Psychiatric Services, 48,* 873-874.

Appelbaum, P. S. (1998). Ought we to require emotional capacity as part of decisional competence. *Kennedy Institute of Ethics Journal, 8,* 377-387.

Appelbaum, P. S., & Grisso, T. (1988). Assessing patients' capacities to consent to treatment. *New England Journal of Medicine, 319,* 1635-1638.

Appelbaum, P. S., & Grisso, T. (1995). The MacArthur Treatment Competence study. I. *Law and Human Behavior 19*, 105-126.

Appelbaum, P. S., Grisso, T., Frank, E., O'Donell, S., & Kupfer, D. J. (1999). Competence of depressed patients for consent to research. *American Journal of Psychiatry, 156,* 1380-1384.

Appelbaum, P. S., Mirkin S, & Bateman, A. L. (1981). Empirical assessment of competency to consent to psychiatric hospitalization. *American Journal of Psychiatry, 138,* 1170-1176.

Appelbaum, P. S., & Roth, L. (1982). Competency to consent to research. *Archives of General Psychiatry, 39*, 951-958.

Bandura, A. (1977). *Social learning theory*. Englewood Cliffs, NJ: Prentice Hall.

Barton, C. D., Mallik, H. S., Orr, W. B., & Janofsky, J. S. (1996). Clinicians' judgment of capacity of nursing home patients to give informed consent. *Psychiatric Services, 47,* 956-960.

Bean, G., Nishisato, S., Rector, N. A., & Glancy, G. (1994). The psychometric properties of the competency interview schedule. *Canadian Journal of Psychiatry, 39,* 368-376.

Beauchamp, T, L., & Childress, J. F. (1994). *Principles of biomedical ethics*. 4th edition. New York: Oxford University Press.

Berghmans, R. L. P. (1992). *Om bestwil. Paternalisme in de psychiatrie. Een gezondheids-ethische studie*. Amsterdam: Thesis Publishers.

Berghmans, R. L. P. (1999). Ethics of end-of-life decisions in cases of dementia: views of the Royal Dutch Medical Association with some critical comments. *Alzheimer Disease and Associated Disorders, 13,* 91-95.

Berghmans, R. L. P. (2000). *Bekwaam genoeg? Wils(on)bekwaamheid in de geneeskunde, gezondheidsrecht en gezondheidsethiek.* Pre-advies Nederlandse Vereniging voor Bio-ethiek, Utrecht.

Berlin, R. M. & Canaan, A. (1991). A family system approach to competency evaluations in the elderly. *Psychosomatics, 32,* 349-354.

Biesaart, M. C. I. H. & Hubben, J. H. (1997). Wilsonbekwaamheid in de praktijk van de gezondheidszorg. *Medisch Contact, 52,* 1179-1182.

Blustein, J. (1993). The family in medical decisionmaking. *Hastings Center Report, 3,* 6-13.

Borry et al. (2004) De empirische wending in de bio-ethiek. *Ethische Perspectieven, maart no 1, 3-5.*

Brink, T. L., Yesavage, J. A., Heersema, P. H., Adey, M., & Rose, T. L. (1982). Screening test for geriatric depression. *Clinical Gerontologist, 1,* 37-43.

Buchanan, A. E., & Brock, D. (1989). *Deciding for others. The ethics of surrogate decision-making.* Cambridge: Cambridge University Press.

Buller, T. (2001). Competence and risk-relativity. *Bioethics, 15,* 93-109.

Carpenter, W. T., Gold, J. M., Lahti, A. C., Queern, C. A., Conley, R. R., Bartko, J. J., Kovnick, J., & Appelbaum, P. S. (2000). Decisional capacity for informed consent in schizophrenia research. *Archives of General Psychiatry, 57,* 533-538.

Cea, C. D., & Fisher, C. B. (2003). Health care decision-making by adults with mental retardation. *Mental Retardation, 41,* 78-87.

Charland, L. C. (1998). Is Mr. Spock mentally competent? Competence to consent and emotion. *Philosophy, Psychiatry & Psychology, 5*, 67-81.

Charland, L. C. (1999). Appreciation and emotion: theoretical reflections on the MacArthur Treatment Competence Study. *Kennedy Institute of Ethics Journal, 8*, 359-376.

Charland, L. C. (2002). Mental competence and value: the problem of normativity in the assessment of decision-making capacity. *Psychiatry, Psychology & Law, 8,* 135-145.

Chell, B. (1988). Competency: What it is, what it isn't, and why it matters. In: Monagle, J. F. & Thomasma, D. C. Eds. *Medical ethics: a guide for health care professionals*. Aspen Publishers, Rockville, MD.

Cicirelli, V. G. (1997). Relationship of psychosocial and background variables to older adults' end-of-life decisions. *Psychology and Aging, 12,* 72-83.

Colby, A., Kohlberg, L., & Abrahami, A. (1987). *The measurement of moral judgment.* Cambridge University Press, Cambridge.

Culver, C. M. & Gert, B. (1982). *Philosophy in medicine. Conceptual and ethical issues in medicine and psychiatry.* Dordrecht/Boston/London: Kluwer Academic Publishers.

Culver, C. M. & Gert, B. (1990). The inadequacy of incompetency. *The Milbank Quaterly, 4,* 619-643.

Damasio, A. (1994). *Descartes' Error: Emotion, Reason, and the Human Brain.* Grossett & Putnam, New York.

Damasio, A. (2000). *The feeling of what happens.* Body, emotion and the making of consciousness. Vintage, London.

Dekkers, W. J. M. (2001). Autonomy and dependence: chronic physical illness and decisionmaking capacity. *Medicine, Health Care, and Philosophy, 4,* 185-192.

Diagnostic and statistical manual of mental disorders, fourth edition (DSM-IV). Washington, American Psychiatric Association, 1994.

Drane, J. F. (1984). Annotations on informed consent for psychiatry. *Bulletin of the Menninger Clinic, 48*, 111-124.

Drane, J. F. (1985). The many faces of competency. *Hastings Center Report, 15,* 17-21.

Dunn, L. B., Lindamer, L. A., Palmer, B. W., Golshan, S., Schneiderman, L. W., & Jeste, D. V. (2002). Improving understanding of research consent in middle-aged and elderly patients with psychotic disorders. *American Journal of Geriatric Psychiatry, 10,* 142-150.

Dymek, M. P., Atchison, P., Harrell, L., & Marson, D. C. (2001). Competency to consent to medical treatment in cognitively impaired patients with Parkinson's disease. *Neurology, 56,* 17-24.

Elliott, C. & Elliott, B. (1991). From the patient's point of view: medical ethics and moral imagination. *Journal of Medical Ethics, 17,* 173-178.

Etchells, E., Katz, M. R., Shuchman, M., Wong, G., Workman, S., Choudhry, N. K., Craven, J. &, Singer, P. A. (1997). Accuracy of clinical impressions and Mini-Mental State Exam scores for assessing capacity to consent to major medical treatment. *Psychosomatics, 38,* 239-245.

Etchells, E., Darzins, P., Silberfeld, M., Singer, P. A., McKenny, J., Naglie, G., Katz, M., Guyatt, G. H., Molloy, D. W., & Strang, D. (1999). Assessment of patient capacity to consent to treatment. *Journal of General Internal Medicine, 14,* 27-34.

Fazel, S., Hope, T., & Jacoby, R. (1999). Assessment of competence to complete advance directives: validation of a patient centred approach. *British Medical Journal, 318,* 493-497.

Fazel, S., Hope, T., & Jacoby, R. (2000). Effect of cognitive impairment and premorbid intelligence on treatment preferences for life-sustaining medical therapy. *American Journal of Psychiatry, 157,* 1009-1011.

Feinberg, L. F. & Whitlach, C. J. (2001). Are persons with cognitive impairment able to state consistent choices? *Gerontologist, 41,* 374-382.

Finch, J. (1987). Research note: The vignette technique in survey research. *Sociology, 21,* 105-114.

Fillenbaum, G. G. (1985). Screening the elderly. A brief instrumental activities of daily living measure. *Journal of the American Geriatric Society, 33,* 698-706.

Fitten, L. J., Lusky, R., & Hamann, C. (1990). Assessing treatment decision-making capacity in elderly nursing home residents. *Journal of the American Geriatric Society, 38,* 1097-1104.

Fitten, L. J., & Waite, M. (1990). Impact of medical hospitalization on treatment decision-making capacity in the elderly. *Archives of Internal Medicine, 150,* 1717-1721.

Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). Mini-mental state: a practical method for the clinician. *Journal of Psychiatric Research, 12,* 189-198.

Freeman, V. G., Rathore, S. S., Weinfurt, K. P., Schulman, K. A. &, Sulmasy, D. P. (1999). Lying for patients: physician deception of third-party payers. *Archives of Internal Medicine, 159,* 2263-2270.

Glass, K. C. (1997). Refining definitions and devising instruments: two decades of assessing competence. *International Journal of Law and Psychiatry, 20*, 5-33.

Gouwenberg, B. M., Jonker, C., Smit, J. H., & Schmand, B. (1997). *Beoordeling van wilsbekwaamheid bij ouderen met dementie. Ontwikkeling van een methode*. Instituut voor Extramuraal Geneeskundig Onderzoek, Vakgroep Psychiatrie, Vrije Universiteit Amsterdam, Amsterdam.

Green, M. J., Farber, N. J., Ubel, P. A., Mauger D. T., Aboff, B. M., Sosman, J. M., & Arnold, R. M. (2000). Lying to each other: when internal medicine residents use deception with their colleagues. *Archives of Internal Medicine, 160,* 2317-2323.

Griffiths, J. (2002). Schriftelijke wilsverklaringen. Juridische en praktische aspecten van negatieve medische-behandelingsinstructies. *Tijdschrift voor Gerontologie en Geriatrie, 33,* 219-223.

Grisso, T. & Appelbaum, P. S. (1991). Mentally ill and non-mentally-ill patients' abilities to understand informed consent disclosures for medication. *Law and Human Behavior, 15,* 377-388.

Grisso, T., & Appelbaum, P. S. (1995a). Comparison of standards for assessing patients´ capacities to make treatment decisions. *American Journal of Psychiatry, 152,* 1033-1037.

Grisso, T., & Appelbaum, P. S. (1995b). The MacArthur Treatment Competence Study. III. *Law and Human Behavior, 19,* 149-174.

Grisso, T., Appelbaum, P. S., Mulvey, E. P., & Fletcher, K. (1995c). The MacArthur Treatment Competence study. II. *Law and Human Behavior 19*, 127-148.

Grisso, T., Appelbaum, P. S., & Hill-Fotouhi, C. (1997). The MacCAT-T: a clinical tool to assess patients' capacities to make treatment decisions. *Psychiatric Services, 48,* 1415-1419.

Haekens, A. (1998). *Beslissingsbekwaamheid in de gerontopsychiatrische context*. Leuven University Press, Leuven.

Health Council of the Netherlands. (2002). Dementia. The Hague: Health Council of the Netherlands, publication no 2002/04.

Hertogh, C. M. P. M. (2004). Wanneer ontstaat de vraag naar wilsbekwaamheid. In: Boersma, F. & Vellinga, A. (red.): *Oud en dement: wilsonbekwaam?* Grafisch bedrijf Hontelé-van Deursen, Roosendaal.

Hertogh, C. & Verkerk, M. (2002). Wilsbekwaamheid en verpleeghuiszorg: een ongemakkelijke verhouding. *Tijdschrift voor Gerontologie en Geriatrie, 33,* 212-218.

Hoge, S. K., Bonnie, R. J., Poytress, N., Monahan, J., Eisenberg, M., & Feucht-Haviar, T. (1997). The MacArthur adjudicative competence study: development and validation of a research instrument. *Law and Human Behavior, 21,* 141-179.

Janofsky, J. S., McCarthy, R. J., & Folstein, M. F. (1992). The Hopkins Competency Assessment Test: a brief method for evaluating patients' capacity to give informed consent. *Hospital and Community Psychiatry, 43,* 132-136.

Joosten, E., Pelemans, W., Hiele, M., Noyen, J., Verhaeghe, R. &, Boogearts, M. A. (1992). Prevalence and causes of anaemia in a geriatric hospitalized population. *Gerontologist, 38,* 111-117.

Kahneman, D., Slovic, P., & Tversky, A. (1982). *Judgment under uncertainty: Heuristics and biases.* Cambridge University Press, Cambridge.

Kim, S.Y., Cox, C., & Caine, E. D. (2002). Impaired decision-making ability in subjects with Alzheimer's disease and willingness to participate in research. *American Journal of Psychiatry, 159,* 797-802.

Kim, S.Y. H., Caine, E. D., Currier, G.W., Leibovici, A. &, Ryan, J. M. (2001). Assessing the competence of persons with Alzheimer's disease in providing informed consent for participation in research. *American Journal of Psychiatry, 158,* 712-717.

Kitamura, F., Tomoda, A., Tsukada, K., Tanaka, M., Kawakami, I., Mishima, S., & Kitamura, T. (1998). Method for assessment of competency to consent in the mentally ill. Rationale, development, and comparison with the medically ill. *International Journal of Law and Psychiatry, 21,* 223-244.

Kitamura, T. & Kitamura, F. (2000). Reliability of clinical judgment of patients' competency to give informed consent: a case vignette study. *Psychiatry and Clinical Neuroscience, 54,* 245-247.

van de Klippe, C. J. (1990). Wilsonbekwaamheid in de psychiatrie: zes benaderingen. *Maandblad Geestelijke volksgezondheid, 47,* 123-138.

Kohlberg, L. (1984). *The psychology of moral development.* Harper and Row, San Francisco, CA.

Kok, R. M. (1994). Zelfbeoordelingsschalen voor depressie bij ouderen. *Tijdschrift voor Gerontologie en Geriatrie, 25,* 150-156.

Kuczewski, M. G. (1996). Reconceiving the family. The process of consent in medical decisionmaking. *Hastings Center Report, 26,* 30-37.

Lapid, M. I., Rummans, T. A., Poole, K. L., Pankratz, V. S., Maurer, M. S., Rasmussen, K. G., Philbrick, K. L., & Appelbaum, P. S. (2003). Decisional capacity of severely depressed patients requiring electroconsulsive therapy. *Journal of ECT, 19,* 67-72.

Lazarus, R. S. & Lazarus, B. N. (1994). *Passion and reason: making sense of our emotions*. Oxford University Press.,Oxford.

Lindemann Nelson J. (1992). Taking families seriously. *Hastings Center Report, 22,* 6-12.

Link, B. G., Phelan, J. C., Bresnahan M., Stueve, A. &, Pescosolido, B.A. (1999). Public conceptions of mental illness: labels, causes, dangerousness, and social distance. *American Journal of Public Health, 89,* 1328-1333.

Lowe, M., Kerridge, I. H., McPhee, J., & Fairfull-Smith, H. (2000). A question of competence. *Age and Ageing, 29,* 179-182.

Mahoney, F. I. & Barthel, D. W. (1965). Functional evaluation: the Barthel Index. *Md State Medical Journal, 14,* 61-65.

Marson, D. C. (1994). Determing the competency of Alzheimer patients to treatment and research. *Alzheimer Disease and Associated Disorders, 8,* 5-18.

Marson, D. C., Annis, S. M., McInturff, B., Bartolucci, A. &, Harrell, L. E. (1999). Errors behaviors associated with loss of competency in Alzheimer's disease. *Neurology, 53,* 1983-1992.

Marson, D. C., Chatterjee, A., Ingram, K. K., & Harrell, L. E. (1996). Toward a neurologic model of competency: cognitive predictors of capacity to consent in Alzheimer's disease using three different legal standards. *Neurology, 46,* 666-672.

Marson, D. C., Cody, H. A., Ingram, K. K., & Harrell, L. E. (1995a). Neuropsychologi c predictors of competency in Alzheimer's disease using a rational reasons legal standard. *Archives of Neurology, 52,* 955-959.

Marson, D. C., Earnst, K. S., Jamil, F., Bartolucci, A., & Harrell, L. E. (2000a). Consistency in physicians´ legal standard and personal judgments of competency in patients with Alzheimer´s disease. *Journal of the American Geriatric Society, 48,* 911-918.

Marson et al. (2000b). Assessing financial capacity in patients with Alzheimer disease. *Archives of Neurology, 57,* 877-884.

Marson, D. C., Ingram, K. K., Cody, H. A. &, Harrell, L. E. (1995b). Assessing the competency of patients with Alzheimer's disease under different legal standards. *Archives of Neurology, 52,* 949-954.

Marson, D. C., McInturff, B., Hawkins, L., Bartolucci, A., & Harrell L. E. (1997). Consistency of physician judgments of capacity to consent in mild Alzheimer's disease. *Journal of the American Geriatric Society, 45,* 453-457.

Martin, B. A., & Glancy, G. D. (1994). Consent to electroconvulsive therapy: investigation of the validity of a competency questionnaire. *Convulsive Therapy, 10*, 279-286.

Martyn, S. R. (1994). Substituted judgment, best interest, and the need for best respect. *Cambridge Quarterly Healthcare Ethics, 3*, 195-208.

Maslow, K. (2004). Dementia and serious coexisting medical conditions: a double whammy. *Nursing Clinics of North America, 39,* 561-579.

Meisel A., Roth L. H., & Lidz C. W. (1977). Toward a model of the legal doctrine of informed consent. *American Journal of Psychiatry, 134,* 285-289.

Mezey, M., Teresi, J., Ramsey, G., Mitty, E., & Bobrowitz, T. (2000). Decision-making capacity to execute a health care proxy: development and testing of guidelines. *Journal of the American Geriatric Society, 48,* 179-187.

Ministerie van Justitie. (1994). *Handreiking voor de beoordeling van wilsbekwaamheid.* Ministerie van Justitie, Den Haag.

Molloy, D. W., Silberfeld, M., Darzins, P., Guyatt, G. H., Singer, P. A., Rush, B., Bédard, M., & Strang, D. (1996). Measuring capacity to complete an advance directive. *Journal of the American Geriatric Society, 44,* 660-664.

Moser, D. J., Schultz, S. K., Arndt, S., Benjamin, M. L., Fleming, F. W., Brems, C. S., Paulsen, J. S., Appelbaum, P. S., & Andreasen, N. C. (2002). Capacity to provide informed consent for participation in schizophrenia and HIV research. *American Journal of Psychiatry, 159*, 1201-1207.

Muncie, H. L., Magaziner, J., Hebel, R., et al (1997). Proxies' decisions about clinical research participation for their charges. *Journal of the American Geriatric Society, 45,* 929-933.

Naglie, G., Silberfield, M., & O'Rourke, K. (1993). A randomized trial of a decisional aid for mental capacity assessments. *Journal of Clinical Epidemiology, 46,* 221-230.

Palmer, W. B., Nayak, G. V., Dunn, L. B., Appelbaum, P. S., & Jeste, D. V. (2002). Treatment-related decision-making capacity in middle-aged and older patients with psychosis. A preliminary study using the MacCAT-T and HCAT. *American Journal of Geriatric Psychiatry, 10,* 207-211.

Pearlin, L. I. & Schooler, C. (1978). The structure of coping. *Journal of Health and Social Behavior, 19*, 2-21.

Peijnenburg, A. J. M. (1996). *Acting against one's best judgement. An enquiry into practical reasoning, dispositions and weakness of will.* Groningen.

Penn, D. L., Kommana, S., Mansfield, M., Link &, B.G. (1999). Dispelling the stigma of schizophrenia: II. The impact of information on dangerousness. *Schizophrenia Bulletin, 25,* 437-446

Pentimone, F., del Corso, L., Frustaci, G., Gnesi, A., Romanelli, A. M., Sabbatini, A. R. (1992). Clinical evaluation of anemia in the aged [Italian]. *Minerva medica, 83,* 35-39.

The President's Commission for the study of ethical problems in medicine and biomedical and behavioral research. (1982). *Making Health Care Decisions*. Washington DC: US Government Printing Office.

Rainville, J., Carlson, N., Polatin, P., Gatchel, R. J. &, Indahl, A. (2000). Exploration of physicians' recommendations for activities in chronic low back pain. *Spine, 25,* 2210-2220.

Roth, L. H., Meisel, A., & Lidz, C. W. (1977). Tests of competency to consent to treatment. *American Journal of Psychiatry, 134,* 279-284.

Royall, D. R., Cordes, J., & Polk, M. (1997). Executive control and the comprehension of medical information by elderly retirees. *Experimental Aging Research, 23,* 301-313.

Rutman, D. & Silberfeld, M. (1992). A preliminary report on the discrepancy between clinical and test evaluations of competence. *Canadian Journal of Psychiatry, 37,* 634-639.

Sachs, G. A., Stocking, C. B., Stern, R., Cox, D. M., Hougham, G., & Sachs, R. S. (1994). Ethical aspects of dementia research: informed consent and proxy consent. *Clinical Research, 42,* 403-412.

Saks, E. R., Dunn, L. B., Marshall, B. J., Nayak, G. V., Golshan, S., & Jeste, D. V. (2002). The California Scale of Appreciation. A new instrument to measure the appreciation component of capacity to consent to research. *American Journal of Geriatric Psychiatry, 10,* 166-174.

Schmand, B., Gouwenberg, B., Smit, J. H., & Jonker, C. (1999). Assessment of mental competency in community-dwelling elderly. *Alzheimer Disease and Associated Disorders, 13,* 80-87.

Schneiderman, L. J., Kaplan, R. M., Rosenberg, E., et al (1997). Do physicians' own preferences for life-sustaining treatment influence their perceptions of patients' preferences. *Cambridge Quarterly Healthcare Ethics, 6*, 131-137.

Schutz, A. & Luchman, T. (1974). *The structures of the life-world.* London, Heinemann.

Sherer, M., Maddux, J. E., Mercandante, B., Prentice-Dunn, S., Jacobs &, B., Rogers, R. W. (1982). The self-efficacy scale: construction and validation. *Psychological Reports, 51,* 663-671.

Silberfeld, M. (1994). Evaluating decisions in mental capacity assessments. *International Journal of Geriatric Psychiatry, 9,* 365-371.

Stanley, B., Guido, J., Stanley, M., & Shortell, D. (1984). The elderly patient and informed consent. *Journal of the American Medical Association, 252,* 1302-1306.

Stanley, B., Stanley, M., Guido, J., Garvin &, L. (1988). The functional competency of elderly at risk. *Gerontologist, 28 (suppl),* 53-58.

Tombaugh, T. N., & MacIntyre, N. J. (1992). The Mini-Mental State Examination: A comprehensive review. *Journal of the American Geriatric Society, 40*, 922-935.

Vellinga, A., Smit, J. H., van Leeuwen, E., van Tilburg, W. &, Jonker, C. (2002). De beoordeling van ouderen met en zonder cognitieve stoornissen: de vignetmethode nader bekeken. *Tijdschrift voor Gerontologie en Geriatrie, 33,* 207-211.

Vellinga, A., Smit, J. H., van Leeuwen, E., van Tilburg, W. &, Jonker, C. (2004). Instruments to assess decision-making capacity: an overview. *International Psychogeriatrics, 16:* 397-419.

Vellinga, A., Smit, J.H., van Leeuwen, E., van Tilburg, W., & Jonker, C (2005). Decision-making capacity of elderly patients assessed through the vignette method: Imagination or reality? *Aging and Mental Health, 9*: 40-48.

Vollmann, J. &, Winau, R. (1996). Informed consent in human experimentation before the Nuremberg code. *British Medical Journal*, *313,* 1445-7

Wang, P. L. & Ennis, K. E. (1986). Competency assessment in clinical populations: an introduction to the cognitive competency test. In: B. P. Uzzell & Y. Gross, Eds. *Clinical Neuropsychology of Intervention*. Dordrecht: Martinus Nijhoff Publishing.

Welie, J. V. M. & Welie, S. P. K. (2001). Patient decision-making competence: outlines of a conceptual analysis. *Medicine, Health Care and Philosophy, 4*, 127-138.

Welie, S. P. K., Dute, J., Nys, H., & van Wijmen, F. C. B. (2005). Patient incompetence and substitute decisionmaking: an analysis of the role of the health care professional in Dutch law. *Health Policy, 73,* 21-40.

Wicclair, M. R. (1991). Patient decision-making capacity and risk. *Bioethics, 5,* 91-104.

Widdershoven, G. & Berghmans, R. (2002). Wilsbekwaamheid in de ouderenzorg. *Tijdschrift voor Gerontologie en Geriatrie, 33,* 201-206.

Widdershoven, G. A. M. (2005). Paternalisme en autonomie. Commentaar op Nys. *Tijdschrift voor Psychiatrie, 47,* 529-531.

Wilks, I. (1997). The debate over risk-related standards of competence. *Bioethics, 11,* 413-426.

Wirshing, D. A., Wirshing, W. C., Marder S. R., Liberman, R. P., & Mintz, J. (1998). Informed consent: assessment of comprehension. *American Journal of Psychiatry, 155,* 1508-1511.

Zweibel, N. R. & Cassel, C. K. (1989). Treatment choices at the end of life: a comparision of decisions by older patients and theis physician-selected proxies. *The Gerontologist, 29*, 615-621.

Curriculum Vitae

Curriculum Vitae

Astrid Vellinga werd op 8 maart 1974 geboren te Harlingen. In 1992 behaalde zij het VWO diploma aan de RSG Simon Vestdijk te Harlingen. In datzelfde jaar startte zij met de studie geneeskunde aan de Vrije Universiteit te Amsterdam. Het artsexamen werd behaald in 1998. Tijdens de studie participeerde zij als student-assistent in het onderwijs medische filosofie en ethiek. Tevens voltooide zij een kwalitatief onderzoek naar de ervaringen van mensen met het postpoliosyndroom. Vanaf 1998 tot 2003 werkte zij bij de vakgroep Psychiatrie en het Centrum voor Ethiek en Levensbeschouwing van het VU Medisch Centrum te Amsterdam. Daar werd het onderzoek verricht waarvan de resultaten in dit proefschrift beschreven zijn. In 2000 rondde zij de postdoctorale opleiding epidemiologie af. Vanaf 2003 is zij werkzaam als arts-assistent psychiatrie bij Mentrum te Amsterdam. Zij is hier vanaf 2004 in opleiding voor psychiater.

Publications

In this thesis:

Vellinga, A., Smit, J. H., van Leeuwen, E., van Tilburg, W., & Jonker, C. (2002). De beoordeling van wilsbekwaamheid bij ouderen met cognitieve stoornissen: de vignet-methode nader bekeken. *Tijdschrift voor Gerontologie en Geriatrie, 33,* 207-211.

Van Leeuwen, E. & Vellinga, A. (2004). Knowing well or living well: is competence relevant to moral experience and capacity in clinical decision-making? In: Thomasma, D. C. & Weisstub, D. N. (eds). *Variables of moral capacity.* Kluwer Academic Publishers, Dordrecht/Boston/London, 187-202.

Vellinga, A., Smit, J. H., van Leeuwen, E, van Tilburg, W., & Jonker, C. (2004). Instruments to assess decision-making capacity: an overview. *International Psychogeriatrics, 16,* 397-419.

Vellinga, A., Smit, J. H., van Leeuwen, E., van Tilburg, W., & Jonker, C. (2004). Decision making capacity: judgements of physicians, family members and the vignette method. *International Journal of Geriatric Psychiatry, 19,* 645-654.

Vellinga, A. & Ederveen, A. (2004). Wilsbekwaamheid: kun je 'goed' beslissen gevaar te lopen? *Tijdschrift voor Psychiatrie, 46,* 395-399.

Vellinga, A., Smit, J. H., van Leeuwen, E., van Tilburg, W., & Jonker, C. (2005). Decisionmaking capacity of elderly patients assessed with the vignette method: imagination or reality? *Aging & Mental Health, 9,* 40-48.

Other publications:

Vellinga, A. (2000). Dementie, schaduw als schrikbeeld. Wijsgerige, ethische en gelovige gezichtspunten. Door: M. Pijnenburg & V. Kirkels. Medische Antropologie, 12, 163-166.

Vellinga, A., Nollet, F., & Oderwald, A. K. (2000). Eén keer polio is één keer polio, en geen twee keer: ervaringen van mensen met het postpoliosyndroom. *Nederlands Tijdschrift voor Geneeskunde, 144,* 871.

Vellinga, A. (2001). Weten door meten? Een nieuwe meetmethode voor wilsbekwaamheid. *Denkbeeld, 13,* 8-11.

Vellinga, A. & Oderwald, A. K. (2001). Goed hulpverlenerschap aan de grens van wils-bekwaamheid. *Nederlands Tijdschrift voor Geneeskunde, 145,* 242-243.

van Kleffens, T. & Vellinga, A. (2001). Weigering van verzoeken om euthanasie of hulp bij zelfdoding meestal gebaseerd op ingeschatte niet-ondraaglijkheid van het lijden, de beschikbaarheid van behandelalternatieven en de aanwezigheid van depressieve klachten. *Nederlands Tijdschrift voor Geneeskunde, 145,* 757-759.

Winagrodzka, A., Wagenaar, R., Bergmans, R., Vellinga, A, Booij, J., van Royen, E. A., van Emmerik, R. E., Stoof, J. C. &, Wolters, E. C. (2001). Rigidity decreases resting tremor intensity in Parkinson´s disease: a [(123)] I beta-CIT SPECT study in early, nonmedicated patients. *Movement Disorders, 16,* 1033-1040.

Vellinga, A. (2003). Hoe beoordeel je wilsbekwaamheid? In: Boersma, F. & Vellinga, A. (eds.) (2003). *Symposiumverslag Leo Cahnstichting. Oud en dement: wilsonbekwaam?* Lundbeck B.V. Grafisch Bedrijf Hontelé-van Deursen, Roosendaal.

Boersma, F. & Vellinga, A. (eds.) (2003). *Symposiumverslag Leo Cahnstichting. Oud en dement: wilsonbekwaam?* Lundbeck B.V. Grafisch Bedrijf Hontelë-van Deursen, Roosendaal.

Abstracts:

Vellinga, A., Nollet, F., & Oderwald, A. K. (1999). Eén keer polio is één keer polio, en geen twee keer. Ervaringen van mensen met het postpoliosyndroom. *Elfde marktdag Medische Sociologie en Medische Antropologie,* Amsterdam.

Vellinga, A. & van Leeuwen, E. (1999). Knowing well or living well: is competence relevant to moral experience and capacity in clinical decision-making? *XXIVth International Congress on Law and Mental Health,* Toronto.

Vellinga, A., Nollet, F., & Oderwald, A. K. (1999). `Once polio is enough´ Experiences of people with post-polio syndrome. *Joint meeting British Society of Rehabilitation Medicine with Nederlandse Vereniging van Artsen voor Revalidatie & Physische Geneeskunde,* Amsterdam.

Vellinga, A. (2000). Wilsbekwaamheid bij dementie. *28e Voorjaarscongres*. Nederlandse Vereniging voor Psychiatrie, Maastricht.

Vellinga, A. & Jonker, C. (2000). Wilsbekwaamheid bij een psychiatrische patiënt. *"Medisch-ethische beslissingen rond het levenseinde van de patiënt in het APZ".* Nederlandse Vereniging van Artsen Somatisch Werkzaam in de Psychiatrie, Ermelo.

Vellinga, A. (2000). Bepaling van wilsbekwaamheid bij dementie. *AIO-dagen psychiatrie,* Zandvoort.

Vellinga, A. & Jonker, C. (2001). Het meten van wilsbekwaamheid bij ouderen met cognitieve stoornissen. *29e Voorjaarscongres*. Nederlandse Vereniging van Psychiatrie, Rotterdam.

Vellinga, A. (2001). Competence: broadening the concept? *Invitational conference 'Capacity and competence'*. Ministerie VWS, Den Haag.

Vellinga, A. & van Leeuwen, E. (2001). Assessing competence: imagination or reality? *XXVIth International Congress on Law and Mental Health,* Montreal.

Vellinga, A. (2001). De Amsterdamse vignetmethode. *Symposium 'Wilsbekwaamheid bij ouderen',* Amsterdam.

Vellinga, A. (2003). Determinanten van wils(on)bekwaamheid vast te stellen door de hulpverlener. *Geriatriedagen.* Ede.

Vellinga, A. (2003). Hoe beoordeel je wilsbekwaamheid. *Symposium Oud en dement: wilsonbekwaam?* Leo Cahnstichting, Ede

Dankwoord

Dankwoord

Het schrijven van een proefschrift vertoont vele parallellen met het concept wilsbekwaamheid: het is complex en beweegt zich op het grensvlak van autonomie en weldoen. Vandaar nu het dankwoord aan allen die een bijdrage hebben geleverd aan deze complexe zoektocht naar vrijheid (lees: totstandkoming van dit proefschrift).

Bovenal gaat mijn dank uit naar al diegenen die geheel belangeloos hebben geparticipeerd in de interviews die wij hebben verricht. De interviews namen veel tijd van u in beslag en bovendien heeft een groot aantal van u ook ingestemd met een tweede interview thuis.

Ook dank voor de diverse afdelingen (geriaters en verpleegkundigen) die hun medewerking hebben gegeven bij de selectie en benadering van mogelijke deelnemers aan deze studie: de dagkliniek Geriatrie van het Slotervaartziekenhuis te Amsterdam (prof.dr. G. Ligthart, drs. J. van Campen), de afdeling geriatrie van het VU Medisch Centrum te Amsterdam (drs. J. Daal en drs. O.J. de Vries), de afdeling gastro-enterologie van het VU Medisch Centrum te Amsterdam (prof.dr. S.G.M. Meuwissen en dr. E. Kuipers), de afdeling geriatrie van ziekenhuis Gooi-Noord te Hilversum (drs. W. van Maarschalkerweerd en drs. C. Rees) en de afdeling geriatrie van het Medisch Centrum Alkmaar te Alkmaar (dr. C. Kalisvaart).

Voorts dank aan de leden voor de beoordelingcommissie voor de aandacht die zij aan mijn proefschrift hebben willen schenken: dr. R.L.P. Berghmans, prof.dr. J. Legemaate, prof.dr. M. Olde-Rikkert en dr. A.F. Tholen. Eveneens dank aan de overige leden van de oppositie: prof.dr. J. Dekker en dr. C.M.P.M. Hertogh voor de aandacht die ook zij aan mijn proefschrift hebben geschonken.

Zoals al eerder genoemd: wilsbekwaamheid is een complex concept, wat onder andere tot uitdrukking kwam in de grote commissie van begeleiders: Cees Jonker (bijzonder hoogleraar Dementie), Evert van Leeuwen (hoogleraar Medische Ethiek), Jan Smit (methodoloog) en Willem van Tilburg (hoogleraar Psychiatrie). De begeleiders zijn van diverse pluimage, wat leidde tot vele boeiende discussies waarbij de verschillende aspecten van het concept werden belicht. Dit onderkennende lijkt het onvermijdelijk dat het ene antwoord dat altijd gezocht wordt, wel eens onvindbaar lijkt. Sterker nog: het zoeken naar antwoorden leidt veelal tot meer vragen. Aangezien deze vorm van complexiteit me erg past, heb ik veelal van deze discussies genoten. Voorts heb ik wel eens cynisch opgemerkt dat de autonomie van een aio kleiner is dan van een oudere met dementie. Als de traditie van de verdediging van stellingen aan deze universiteit zou bestaan, had ik deze stelling graag besproken. Ik laat hier verder buiten beschouwing hoe het met het streven naar weldoen van deze begeleiders en het streven naar autonomie van ondergetekende is verlopen.

Ten eerste wil ik jullie als groep bedanken, omdat zonder de discussies dit proefschrift naar mijn idee minder rijk van inhoud was geworden. Verder ben ik oprecht blij dat ondanks de stoelendans aangaande het promotorschap we als groep dit project tot een proefschrift hebben kunnen afronden.

Ten tweede wil ik jullie individueel bedanken:

Cees Jonker, dank voor je enthousiasmerende coaching tijdens het veldwerk van dit onderzoek. Verder bewaar ik goede herinneringen aan de ochtenden voor acht uur op de O-gang. Ook ben ik je dankbaar voor het uit eindelijk 'vlot' trekken van mijn proefschrift tijdens de lastige laatste periode.

Evert van Leeuwen, dank voor de wijze waarop je je analyserend vermogen hebt aangewend om mijn eigen creativiteit te stimuleren. Ik heb je vaak aangegeven dat ik de door jou geboden vrijheid wel eens te groot vond, maar je weet als geen ander uit te gaan van de inbreng van de promovendus. Daarvoor ben ik je zeer erkentelijk. Verder bewaar ik vele goede herinneringen aan onze buitenlandse 'uitspattingen' en hoop dat we in de toekomst onze samenwerkingsmodus kunnen hervinden.

Jan Smit, dank voor je methodologische bemoeienis met dit proefschrift. Je begeleidde me ondanks je aanvankelijke reserves (arts en statistiek kunnen niet samengaan, toch?) op mijn eerste schreden van statistiek en databeheer. Ik stel je 'down to earth' mentaliteit erg op prijs.

Willem van Tilburg, hoe kun je toch altijd weer die ene simpele maar toch altijd wijze opmerking maken? Dank voor het feit dat je tot het eind in meerdere opzichten betrokken bent gebleven: ik vind het een eer je als co-promotor te hebben (dat kunnen vast niet velen mij nazeggen).

Vervolgens wil ik de interviewers *Krista, Pauline, Jannie en Joske* bedanken, die er mede voor gezorgd hebben dat de dataverzameling succesvol is verlopen. *Marleen van der Horst*, ook jou wil ik bedanken voor de interviews, de interview-training en de coördinatie van de dataverzameling. Ik vind het fijn dat je me ook tijdens de promotie wil bijstaan.

De complexiteit openbaarde zich eveneens in het feit dat ik gedurende het onderzoek onderdeel heb uitgemaakt van diverse afdelingen en onderzoeksgroepen. Dit heeft me altijd een gevoel van vrijheid gegeven. Voordat ik deze afdelingen ga benoemen wil ik eerst een stapje terug in de geschiedenis om *Robert Wagenaar* te bedanken. Robert, jij hebt me enthousiast gemaakt voor wetenschappelijk onderzoek met de zoektocht naar rigiditeitspatronen bij mensen met de ziekte van Parkinson.

Mijn thuisbasis vormde lange tijd de gang met onderzoekers van het LASA (Longitudinal Aging Study Amsterdam) project. *Dorly Deeg* bedankt dat je mij als vreemde eend in de bijt hebt geadopteerd en me profijt hebt laten trekken uit de onderzoeksbesprekingen die in het kader van het LASA project werden georganiseerd. Ook dank aan alle andere collega's van LASA: ik ben mede door jullie altijd met veel plezier naar mijn werk gegaan. In het bijzonder dank aan *Marja Aartsen, Miranda Dik, Suzan van der Pas en Lissy Terhell*. De AIO-etentjes boden altijd een welkome vrijplaats om eens flink over de promotieperikelen te spuien. Suzan: nu jij nog en dan kunnen we verdergaan met doctor-etentjes! Ook dank aan de verschillende kamergenoten met wie ik lief en leed heb gedeeld, met name wil ik hier Pauline Spaan en France Portrait noemen. Pauline, je was een maatje van het eerste uur. France, je bent met name tijdens het eindtraject tot steun geweest (weliswaar niet meer als kamergenoot).

Verder maakte ik onderdeel uit van de afdeling Metamedica. Dank aan alle collega's voor de discussies die een heel ander karakter hadden dan de epidemiologische invalshoek van LASA. *Arko Oderwald* bedankt voor het begeleiden van mijn eerste schreden op het gebied van kwalitatief onderzoek. *Frans Meijman* dank voor je ontnuchterende onorthodoxe visie op de wereld. *Gerrit Kimsma,* fijn om een mede-Fries te hebben in het 'wilde' westen. Jammer dat we dit niet meer met *Dave Thomasma* kunnen delen. Verder dank aan *Berna van Baarsen*. Behalve als collega bij LASA en Metamedica heb ik me met name in de laatste fase van dit project door je gesteund gevoeld. Tot slot dank aan *Titia van Kleffens* voor de vele discussies met of zonder inhoud en de vele (on) wetenschappelijke activiteiten die we met onze Fiats bezochten. Ik vind het fijn dat je me tijdens de promotie zult bijstaan.

Behalve deze afdelingen heb ik wetenschappelijke discussies kunnen voeren in gezelschap van vele enthousiaste collega's in twee onderzoeksscholen: Care en de Onderzoeksschool Wetenschap, Technologie en Moderne Cultuur. Dank hiervoor.

Geheel toegespitst op het onderwerp wilsbekwaamheid bij ouderen was de multidisciplinaire discussiegroep van de Leo Cahnstichting. *Froukje Boersma* wil ik bedanken voor het gemeenschappelijk voorzitterschap en tevens wil ik alle deelnemers bedanken die allen (soms van grote afstand komend) de moeite namen om over dit onderwerp van gedachten te wisselen.

Dit brengt mij op een aantal mensen die behalve onderdeel van deze groep ook op andere wijze een inspiratiebron vormden. *Ron Berghmans*, vanaf het eerste moment (een Medilex bijeenkomst in 1998) heb je me geïnspireerd. Je zienswijze op de problematiek dwong me om de geijkte paden van de liberale ethiek los te laten. Ik ben vereerd dat je in mijn oppositie wilt deelnemen. *Ruud van Beest*, met plezier denk ik terug aan onze discussies in Canada. *Sander Welie*, het is fijn om een 'brother in arms' te hebben. Ik hoop dat jij ook spoedig jouw proefschrift over wilsbekwaamheid kunt afronden.

Er is ook werk na en naast het proefschrift! *Robert Schoevers* wil ik bedanken voor zijn vertrouwen door mij in opleiding voor psychiater aan te nemen bij Mentrum. Ook dank voor je belangstelling en betrokkenheid bij de totstandkoming van dit proefschrift. En ja: het is inderdaad een jaar later. Ook bij Mentrum waren er de nodige discussies over wilsbekwaamheid in de psychiatrie in de werkgroep onder leiding van Albert Blom. Alle deelnemers dank voor de zinvolle aanvullingen uit de dagelijkse praktijk aan mijn theoretisch geschoolde geest. Met name wil ik *Hans Nusselder* bedanken, ook in zijn rol als werkbegeleider. Tja, wat betekent autonomie op een gesloten afdeling? Ik wil je in het bijzonder bedanken voor het niet bespreken van de proefschriftperikelen. Je wist me altijd in de realiteit van het SPDC te houden, waar je me stimuleerde tot het ontdekken van mijn eigen stijl als psychiater. Tot slot dank aan alle collega's van Mentrum voor het fijne werkklimaat, maar in het bijzonder nog *Marië Nijpels* en *Bas Frelier,* mijn maatjes in opleiding van het eerste uur.

En last but not least er is ook leven na het werk! Ook al leek deze vrijheid menigmaal te worden ingeperkt door het proefschrift, juist degenen die deze aspecten van het leven met mij delen hebben de uiteindelijke afronding mogelijk gemaakt. Lieve familie, vrienden en vriendinnen dank voor jullie bereidwillig oor en acceptatie voor alle momenten dat ik weer eens niet contact met jullie opnam. Verder dank voor de gezellige etentjes *(Michiel & Tanja, Jeroen & Catelijne, Berna & Mark, France & Erik, Isis & Femke, Carla & Ron)*, fijne uitjes en vakanties *(Maarten, Renate & Timo)*, spelletjesdagen en weekenden *(Petra & Manje)*, en sportactiviteiten (ja beste waterpoloërs: ik zal nog trouwer komen trainen, en *Judith Franssen* bedankt voor de mooie lay-out).

Ik wil besluiten met de kleinste kring van naaste betrokkenen. *Malu en Martijn* het lot heeft ons samengebracht en ik ben blij dat jullie onderdeel zijn van mijn leven. *Martijn* en *Jellie* ik ben blij dat jullie weer van de partij zijn. *Malu* dank voor je steun de afgelopen jaren en meedenken over het (knal) feest. Overigens je te zien opgroeien van een wijsneus van elf tot een mooie zelfstandige vrouw was ook al een feest. Fijn dat je samen met *Remco* van de partij bent. *Ma*, dit is nu het resultaat van de afgelopen jaren werk naast het werk. Dank voor je altijd onvoorwaardelijke medeleven.

Mijn ouders, dank dat jullie me altijd gestimuleerd hebben om datgene te doen dat mijn belangstelling had. Ook dank voor het medeleven én de praktische ondersteuning de laatste jaren, al besef ik dat oppassen ook niet geheel onbaatzuchtig is. Pa, je hebt er een mooie voorkant van gemaakt!

De laatste woorden zijn bestemd voor mijn 'ventjes'. *Florian* niet geheel volgens plan heb je toch nog het besef van het 'boekje maken' meegekregen. Het is nu klaar: tijd voor vele spelletjes mens-erger-je-niet! Verder heb je met je komst een behoorlijke dosis aan relativering gebracht: iets wat zeker het afronden van een proefschrift bevordert. *Murk* ik ben je met name dankbaar voor de vele jaren die we nu al gezamenlijk genietend en met passie doorbrengen. Met jou aan mijn zijde heb ik uiteindelijk de grenzen gevonden en het proefschrift weten af te ronden. Wat een vrijheid in afhankelijkheid én simpliciteit (als tegenhanger voor mijn hang naar complexiteit)!